**REPORT OF PROCEEDINGS BEFORE** 

# **COMMITTEE ON LAW AND SAFETY**

# INQUIRY INTO MANAGING INFORMATION RELATED TO DONOR CONCEPTION

At Sydney on Monday 29 April 2013

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The Committee met at 11.15 a.m.

PRESENT

Mr G. D. Barilaro (Chair) Mr G. K. Edwards Mr N. Lalich Mr G. Zangari SHARON SWINBOURNE, Assistant Registrar, Registration Services, New South Wales Registry of Births, Deaths and Marriages, and

LISA KARAM, Manager of Amendments, New South Wales Registry of Births Deaths and Marriages, sworn and examined:

**CHAIR:** I declare the public hearing open. Thank you for attending this hearing of the Law and Safety Committee's Inquiry into Managing Information Related to Donor Conception. This inquiry is examining the way information that relates to people conceived by donor conception before 2010 is managed. A range of questions are being looked at including whether retrospective access to information should be granted, what issues this may raise with individuals and donors, what support should be provided, and how donor information should be managed and by whom. Can you confirm that you have been issued with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses, and do you have any questions concerning these procedures?

Mrs SWINBOURNE: Yes we have them and we do not have any questions.

Ms KARAM: The same.

**CHAIR:** Have you provided the Committee with a submission and do you want that submission to form part of your formal evidence?

**Ms KARAM:** There is a whole-of-Government submission, No. 18, which the registry has contributed to. We will not be submitting anything else unless we are asked.

CHAIR: Would you like to make an opening statement?

Mrs SWINBOURNE: No, the registry does not want to make an opening statement.

**Mr NICK LALICH:** The Committee has received evidence that in other jurisdictions where the donor register is managed by the Registry of Births, Deaths and Marriages a comprehensive service including counselling and information release is not always provided. Can you comment on the New South Wales registry's ability to provide a service encompassing these elements?

**Ms KARAM:** The registry is not well placed to provide counselling services in relation to our products and services. The registry does have the capacity to provide an information release service similar to the model used for the release of adoption information. Adoption information is released by the registry after a supply authority from the Director General of the Department of Family and Community Services is obtained and submitted to the registry by the applicant. The counselling component is provided by Family and Human Services. The registry's core function is to register events as set out in the Births, Deaths and Marriages Registration Act 1985. A move to provide counselling services to people applying for the release of donor conception information would fall outside the scope, structure and current function of the registry.

**Mr GARRY EDWARDS:** Can you outline the technical implications of setting up a register that would contain retrospective donor conception information?

**Mrs SWINBOURNE:** Retrospective information relating to donor conceived births that have occurred in New South Wales would need to be provided by Family and Community Services to the registrar in a similar way to that described by Ms Karam in answer to your first question. Once we had that information we could put a flag in the register against a particular birth. The flag would indicate that the birth was a donor conceived birth and then a separate file containing the donor details would be made and the nature of the provision of the sort of information we keep would be done through legislation, so the legislation would tell us what to keep.

It would be kept separately so that privacy issues would be adhered to for both the donor and the person who was the result of the donation, the offspring. Presently, the registry's data management system has different levels of access for staff. We basically work on you get access to what you need to do your job. For example, I do not have access to the register. I can, but I do not need it to do my job, so I choose not to have it. Access to the files would be limited to the staff who are actually working in that area. Somebody who is working in a totally different area would not have access to this sort of information. Now, when the person applies for their birth certificate, once they turned 18 that flag would come up and say this person is actually entitled to have that information now, because the flag would show us that. Once the person turns 18, they would get the information that was in that separate file.

**CHAIR:** You have that ability currently with the technology, the programming and procedures that we have got?

**Mrs SWINBOURNE:** Yes. What would happen is that the person would apply for their birth certificate, the registry would send a letter advising there was more information available because that person may or may not know that. Their parents may have applied for their birth certificate in the first place. The parents may not have alluded to the fact that there is more information available. The person would apply to us and then we would send a letter saying there is more information available to them. Then the health authority would be able to provide appropriate services, like counselling and that type of service, and then they would bring, as Lisa described before, a supply authority to us that would show us, yes, it is okay for us to release that information to them. It is the same model that we have for adoptions.

Ms KARAM: That is why we have the technology.

Mrs SWINBOURNE: We already have this.

Ms KARAM: There is a similar indicator within the system that the registry uses to manage its data at this point for adoption, so we do not see it as an issue.

**Mrs SWINBOURNE:** If I could just say one more thing. Prior to the establishment of the registered donor in 2010, there was not actually any government controlled register for private arrangements for artificial reproductive technology. We believe the key to the successful provision of this service is being able to provide correct information and information thart has been verified and the information needs to be of high quality and it needs to be accurate so that person does not receive information that is going to make them distressed, or they find out later it is not right. If retrospective donor conception information relating to private or non-medical arrangements were accepted, the integrity of the register could be compromised. It is unlikely we would able to verify that information.

**Mr GUY ZANGARI:** I was going to touch on the information given once a donor conceived individual turns 18 and they have received the letter. How is that information then given to them as far as the details and information?

Mrs SWINBOURNE: That would be dependent on how the legislation is written.

**Ms KARAM:** It would be dependent on the legislation. The model that we propose is that it would be an addendum that we would send saying, "There is further information available about your birth." What that further information is is a matter for government. However, I guess your question is how would they know? Even with this model somebody is still getting information that they did not have for the first 18 years of their life, that there is more information available about their birth. That is a Victorian model. It still does raise questions. It still is complex, even with what could be considered best practice model. I think it is a good question.

Mr GUY ZANGARI: That is my concern. To say there is more information, there is an addendum, but then—

Ms KARAM: Yes, what is it?

**Mr GUY ZANGARI:** —if there is information available, the presentation of that information in the form and how the individual receives that information is interesting.

**Mrs SWINBOURNE:** The answer to your question pinges on, I think, some of the answers to some other questions that we have received, because there is a lot of "We could do it this way, we could do it that way, and the outcome of this could be very different to the outcome of that." As Lisa said, there are issues no matter which way you do it. You have to be very cautious when you approach this to make sure that any information that is given—it goes back to my point where the integrity of the register, from our perspective, is paramount to us because we are providing, as you are saying, that information to people.

#### Mr GUY ZANGARI: Absolutely.

**Mr NICK LALICH**: Following on from that, Sharon, you are talking about the integrity of the register. If the person is 18 years old, the information you would have would be 18 years old. There may not be too much updating of that information.

# Mrs SWINBOURNE: That is true.

**Mr NICK LALICH:** You could only give the information you have. We take it that it is good because at the time of the donation it would have been verified and logged, and it would be correct. I went to England last year and spoke to their people. They have a standalone register. They do not put it with births, deaths and marriages. The way they give information is that they do not flag anything on the birth certificate or drivers licence. What they say is if the person comes and asks us, they know we will give them the information. They will not give them the information if they go through their whole life never asking. They felt that by giving them the information at 18 years old, it could devastate their whole lives. The person could go through their whole life thinking, "This is mum and dad and I am happy with them." They do not think there is anything else. When you give them that information, it could devastate that person and ruin their whole life and their family. They only give the information if the person asks for it and they know. If they do not know, they never tell them. There is no flag, nothing. It is only if the person knows by mum or dad telling them.

Mrs SWINBOURNE: That is a viable argument.

Mr NICK LALICH: I thought that was a good argument.

**CHAIR:** The case in Victoria is that once it is triggered that there is information available, there is a counselling process to go through before any information is released. We know that is limited.

Mr NICK LALICH: That is by the donor conceived person.

**Mr GUY ZANGARI:** I am Guy Zangari, the member for Fairfield. The submission of the New South Wales Government outlines several options for retrospective access, one of which involves allowing access only to information that the donor has consented to being provided. How would such an option be managed from an administrative and information release point of view?

**Ms KARAM:** The task of administering the recording and releasing of donor conception information poses ethically complex questions. The consent of the donor may dictate if identifying or non-identifying information is released to the donor conceived person. Failure to obtain the consent of the donor could result in breaches of privacy. If the technical process that we outlined in question 2 was implemented, the registry would be provided with supply authority issued by family and community services that would advise whether identifying or non-identifying information was to be released to the donor conceived person.

The registrar does have the power to release a certificate that does not contain all the information that is contained in the register. That might be of note. From an information release perspective, the release of donor conception information would be included in the registry's access to information policy. This policy sets out clear guidelines to the public. It is a published policy. It shows the public the clear guidelines for accessing registry information, such as things like entitlement, identification requirements in relation to the Births, Deaths and Marriages Registration Act and relevant privacy legislation.

**CHAIR:** What resources and experience do you have to undertake public awareness and education campaigns in sensitive areas such as donor conception?

**Mrs SWINBOURNE:** We have had some experience on a smaller scale in undertaking public awareness education programs in sensitive areas. However, it is limited to the legislative changes that have significantly altered our Act. The best example we can provide is the Miscellaneous Acts Amendment (Same Sex Relationships) Bill 2008. It had a significant effect on births, deaths and marriages and lots of other legislation. It allowed female same-sex parents to appear on birth certificates. We provided information to the public via our website, through hospitals and at different outlets in terms of explaining that this is the legislation and this is what you have to do to apply to have both same-sex parents on a birth certificate. That was the legislative requirement and we provided the information about how to do it.

However, in terms of awareness campaigns of this nature, that is way out of our field of expertise. That would be the function of another government department or a communications function undertaken by the Attorney General's Department. We are a self-funded government enterprise, so we have to make our own money. We pay money to Treasury, so we charge for our products and services because we need to be able to do that. We have very limited marketing exposure, experience and resources. We can say what the legislation provides and explain what people can do.

Ms KARAM: The amendments providing for the inclusion of same-sex female parents on New South Wales birth certificates were retrospective, so there was considerable interest from the public.

**Mr NICK LALICH:** Could you separate the contact information from the information about physical health and so on? A person might want to know what sickness their father experienced for their future wellbeing. That could be separated from the name and address so that that information could be provided. The child might also be given a name but no address. That would be something; they would know that their father was John Brown. Does the integrity of the register ensure that that is not messed up where the donor has said that he does not want contact—he does not mind information being provided but he does not want contact?

**Mrs SWINBOURNE:** We are calling it a supply authority, for want of another term, because that is what we have in place for adoption. The information we provide to the applicant, whether it be the donor or the donor conceived person, would depend on what the supply authority said. That would then depend on what the Government put in place when the legislation was passed, whether it be that the donor can pick and choose how it is done, what information they want and so on. Individual cases may be different. That is what we do with adoptions; we release whatever the supply authority says we can release.

Mr NICK LALICH: And the integrity would be fine?

CHAIR: Are you talking about more controls?

Mr NICK LALICH: A junior staff member might provide all the information.

**Mrs SWINBOURNE:** That depends on who has access. We have different levels of access and privilege in our system. For example, if it were in a particular area, that area would assign certain levels of staff to be able to release that information.

**Ms KARAM:** Only two staff members have full access to all the adoption information held by the registry. As an internal control measure we have two staff checking it. The supply authority states that the registrar is to release certain information and a clerk will prepare the information and the certificate covering what will be released to the customer. A second staff member will check that, so it is double checked.

Mr NICK LALICH: That is what I am asking about.

**Ms KARAM:** That applies to change of name registrations, adoptions and things like adding and removing paternity information. We manage a lot of sensitive and complex issues. Those controls are regularly reviewed and updated. Our identity security division advises the registrar on matters relating to internal controls.

CHAIR: Have we ever stuffed up in the adoptions area?

Ms KARAM: That is a hard question. We have been in business since 1856.

CHAIR: What about in modern times?

**Ms KARAM:** I cannot recall. I am the operations manager in the amendments area, but that is a misnomer because we deal with adoptions, changes of name and matters of paternity. I have been in that role since 2008 and I have not managed any situation where unauthorised adoption information has been released.

**Mrs SWINBOURNE:** It would be irresponsible of us to say that we will never made a mistake because where there is human intervention or human contact there is always a possibility that mistakes will be made. However, we can categorically state that we do everything physically possible and implement every kind of check to ensure that it does not happen. Under the legislation the registrar is bound to ensure that the register

has the most up-to-date information and its integrity is paramount to us and our staff. We spend a lot of time training people. Every staff member must attend code of conduct training and handling sensitive information sessions twice a year. Every person in the registry is also subject to random audits. They examine who has been looking up records. Staff can be asked at any time why they looked up a record or why they released information. We are audited constantly, both external and internally. That must happen because of the nature of what we do.

CHAIR: I was teasing out the point made by Mr Lalich.

**Mr NICK LALICH:** Do you have any comment about the way in which additional services such as counselling or genetic testing could be funded?

Ms KARAM: That is a matter for government to decide. We do not have any comment about how those services should be funded.

Mrs SWINBOURNE: That is outside our scope.

Mr NICK LALICH: That is part of the legislation and it is a government decision.

**Mrs SWINBOURNE:** Yes. If someone wants a certificate we charge them and if someone over 18 wanted extra information, depending on the form, they would probably be charged as well.

CHAIR: You said you are self-funded.

Mrs SWINBOURNE: That is correct.

**Mr GARRY EDWARDS:** The New South Wales Government submission offers four possible options regarding retrospective access. Would any of them be easier to implement than the others? If so, why? Do you believe that one has particular merit over the others? If so, why?

**Mrs SWINBOURNE:** I have made some notes after referring to the Government submission that referred to four possible options. One of the things I would say is that it was a little bit confusing with that document because question two it used the term "access to information" but question three talked about "contact". In my opinion they are two different things. Access to information and the contact between the donor and the donor-conceived person, and how that might work to me are totally two separate issues.

### CHAIR: I agree.

**Mrs SWINBOURNE:** To answer question six, as set out in question two of the Government's submission the information provided would be in different varying forms. So it is saying that the donor would be able to get limited access, whereas the donor-conceived person would be able to get full access. Privacy issues of the donor would need to be considered if you were going to go down this path because it appears to me that the donor does not have any control over what information is being given out. Given the fact that this is retrospective, and that this person may have made a donation 20 years ago thinking "I don't really want to have any access" or "I don't want to know anything about this, I am just donating". Then to say 20 years down the track this person is going to get all my details, it could be seen as being discriminatory against the donor because they do not have any control over what is being given out about their own privacy because the donation was made in an environment that was more closed than it has been since 2010.

My understanding is that previous to 2010 one could donate anonymously whereas now they can't which is a good thing. People who did donate anonymously were under the impression at the time that they just had to donate and they would never another word about it. In that option, to me it is like they have got no control over what people are going to find out about them. I am playing the devil's advocate with these options to just let the Committee know what are the negativities and the positives. Limited access to medical and non-identifying access, yes, it would satisfy the interests of the donor-conceived persons and it would protect the privacy of the donor. Again, having access to information and contacting donors and donor-conceived people are separate issues.

Access between parties in terms of contacting each other is really out of our scope of operation. I personally would not recommend, or the registry would not recommend any access method that was not

controlled by some sort of intermediary body. In adoptions, there is an organisation called PARK which you may or may not have heard of and they act as intermediaries between adopted persons and their adopted parents. They provide the counselling because it does not always end well. It is not always an easy thing to do. There are a lot of issues. There are other family members that are involved. It is not necessarily just those two people. Having limited access to only medical and non-identifying access is an option but then that part of the whole of government response then goes on to talk about the contact part of it which really we are not qualified to comment on because, I mean, people who work in family and human services, and organisations like PARK and Link-up and all those, that is their expertise. They are trained to do all that.

Option three where the donors are given options to nominate the preferred method of contact seems to be the most practical to implement. This would be the easiest. It is less complex. When it is less complex then there are less chances of errors. There are less chances of giving out incorrect information and information that could be considered a breach of privacy to either of the parties. This option protects the donors who, as I said before, may have not had any intention or desire for any offspring to contact them, or for them to have any access to any children who may have been born as a result of their donation. But it also allows those who are happy to share their information, who would like to do that, who are more than happy to be contacted by any offspring as a result of their donation, it gives them the option to be able to contact them and to be able to give out their private information if they want to.

It also protects agencies such Births, Deaths and Marriages and Family and Human Services because they are guided by what the donor has said they are prepared to release. Again, that would be done through legislation so if the donor said, "Yes, I am happy for Family and Human Services to release all of my information" that is great and we would get by authority, or whatever it may be called. We would could give that information out to that person but then it protects those who may say, "No, I do not have a problem if this person knows A, B and C but I don't want them to know X, Y and Z." To me, that is a good option because it is practical, would you agree?

Ms KARAM: I agree, and it is easier to implement.

**Mrs SWINBOURNE:** And it is easier to implement. Whereas when you go into option four, the contact veto, that gets very complex because there are different levels of the veto. You have to think about who would control that. If someone said, "I don't want to be contacted for 10 years." Who would control that? How would that controlled? It could get very messy. It could lead to information being released to which the donor has not agreed. When you think about it, when policies are written from legislation, a lot of the time it can be a little bit like Chinese whispers sometimes because staff change, registrars change, managers change, interpretations change and so it can come down where the policy was interpreted this way and then 10 years later it was interpreted by different people in different ways and so information could get given to people that was not intended for that to happy because this veto system appears to be so complex and have so many different levels.

If you make it cut and dry and say either "Yes, I am happy for all of my information to be given to the people who were born through donor conception" or "Yes, I am happy for some of my information ..." It is very clean, whereas if you start going into all of these different levels of veto it can get very messy. As a government department we do what the legislation tells us to do. If the Government says, "You will have a veto" and this is how you are going to do it, we will work it out.

**Ms KARAM:** The thing is I think that leads to is it user-friendly for the donor-conceived person or the donor? If it is very complex and if it changes within the 10 years veto, this is a 15 year veto I think it becomes complex for the applicant as well, as a legal question.

**Mrs SWINBOURNE:** That is right. What happens if someone gave a 15 years veto but then changed their mind? There is a lot of risk management around that.

**CHAIR:** The Committee needs to hear that. The members of this Committee may be party to designing that legislation and we have to make sure it is legislation that is practical. That is why it is important to hear your message.

Ms KARAM: Practical for everybody.

**CHAIR:** That is correct.

**Mrs SWINBOURNE:** That is right because the cleaner it is then the less likely are errors of privacy issues. As I said, it is not just two people there are lots of other family who are involved as well. There are a lot of players in this that sadly this legislation can effect.

**Mr GUY ZANGARI:** The Committee has received evidence which compares the situation of donorconceived people wanting access to their genetic information with that of adopted people. Will you outline your understanding of the main similarities and differences in those two circumstances?

**Ms KARAM:** First, the similarities. Both issues relate to identity and connection with family and as such are highly emotional for applicants. Both issues also relate to heritage and cultural identity, and it is strong in both the case of adopted people and donor-conceived people. The third and probably the most relevant to this inquiry is that issues for both donor-conceived people and adopted people are often experienced by people who are seeking information for medical reasons that maybe urgent or potentially life-threatening. The stress on both groups: adoptees and donor-conceived people, surrounding these applications should not be underestimated nor the sensitivity of them. That is what I see as the main similarities.

The main difference is people seeking adoption information, both parents and adoptees, and people seeking donor conception information, in particular donors, is a question of choice. A donor has no imperative to donate genetic material; it is a matter of choice. In contrast, people who have presented their children for adoption often have not had any choice but to do so. The issue of choice from the Registry's perspective is the main issue. The other difference that I would note is that the communities affected by adoption and donor conception are diverse socially, economically and often geographically as well. The Registry holds adoption records from many, many years ago. People affected by adoption come from a wide variety in age. People affected by donor conception is a different generation; a different community. As I have said, economically and socially those groups are very different. Would you like to add anything?

Mrs SWINBOURNE: No, I think that has covered it.

CHAIR: Is there anything else you would like to add?

Ms KARAM: No.

**Mrs SWINBOURNE:** The only thing I guess from the Registry's perspective that we see as important is that anything to do with issuing information to donors or to donor-conceived persons is driven by legislation, and good, clear legislation from our perspective—I am sure Family and Human Services would probably say the same thing. I think good, strong, clear legislation is the key—obviously it is otherwise you would not be having this inquiry. I hope we have answered your questions. Is there anything you wanted to ask us outside of what we have already spoken about?

**Mr NICK LALICH:** I heard what was said in the answer to the last question but to my mind adoption and a donor-conceived person are very similar. Although one is helping somebody out, the other one is if somebody has a child and decides financially or for whatever reason that they cannot handle it so they pass the child up for adoption. At the end of the day the information required is very similar—they want the genetic information or the health information. Sometimes I think when I try to clarify it that the information you pass on for an adopted person, and the reason you pass that information on, would be very similar to a donor-conceived child. At the end of the day there is really no difference between the children.

**Mrs SWINBOURNE:** There is not if you look at it from a technical perspective. If you are looking at it from purely an information release then the terminology you are using is quite true. In our experience though you have to remember, as Lisa said, a person who has donated their sperm most of the time has not seen this child. A person who has had a baby has been through nine months of pregnancy, they have given birth to this child and they have sometimes held this child in their arms. As you know with recent events, people had children taken from them. They were told that they had died, and the children had not died.

Yes, I understand what you are talking about in terms of terminology and on paper but in reality, as Lisa said, you are dealing with a different dynamic because of the very nature of what it is. It is sort of like a bit of a finite versus infinite in a way because that person goes along and they donate their sperm and they leave. They do not actually see what the outcome of that donation is. For previously to 2010 it maybe never, it could be in a few years' time, it may be 30 or 40 years down the track, whereas the adopted mum or the adopted dad—

there are lots of adopted fathers out there who did not even know they were a father because back in days gone by sometimes the woman may not have released that information to that person.

A lot of dads come into the Registry that have found out over the years that they may have a child and they come in with DNA results or whatever and they want to have their name added to a child's birth certificate. It is highly emotional. When you are dealing with these situations there are similarities in terms of when you are using that terminology but in reality it is a little bit different in the structure of what they are doing. Every case is different. It is very difficult to apply one size fits all to these things but obviously you need to as much as possible. Again this is going back to the legislation because when we do anything at the Registry we say, "What does the legislation say that we can do? What does the legislation say that we cannot do?" That is how we work.

**CHAIR:** The Committee members seated at this table sat through the apology for forced adoptions in Parliament last year, which was touched on a minute ago. I am sure through the adoption process the lack of information that has been around was part of the problem in resolving those outstanding issues.

# Mrs SWINBOURNE: Absolutely.

**CHAIR:** We are trying to find a solution but there is no easy fix. It also has to be practical. We are talking about Government putting legislation in place to force people to give us information of high integrity but in real terms a lot of the donor-conceived arrangements are private arrangements outside of the clinics and outside of any formal process. Regardless of what legislation we put in place and what we ask to you to do in meeting that legislation in record keeping, I think we will continue to struggle as to where we go with this.

**Mrs SWINBOURNE:** Absolutely. Unfortunately, when you are dealing with legislation it does not matter what you do but in these sorts of situations you cannot please every constituent because, as I said, everyone has a different story and everyone has different needs. It is highly emotive and everyone wants their needs meet, which is a normal human reaction. Privacy issues are one of the key things here, which is why option three seemed liked such a good option to me. It gave everyone a fair, equitable piece of the privacy cake. It was not sort of as loaded as some of the others and it was not as complex as some of the others. I do not envy your job.

**CHAIR:** At the minimum I suppose one of the outcomes the Committee must come up with at the end of this process would be to protect the information we have for the future. Indeed, we have seen examples where in the hands of private clinics that information has been lost or destroyed deliberately at times. At the minimum what we need to ensure is that through government agencies—be it a national register or a State by State register—that we have good information and that it is protected for the long term?

# Mrs SWINBOURNE: That is right.

CHAIR: In case of changes in legislation in the future around privacy and everything else.

**Mrs SWINBOURNE:** Anything that you do retrospectively is difficult. As I said earlier, the Registrar could not verify the validity or the quality of anything that came through a private arrangement. That is why the supply authority model worked so well; it is coming from the people who are the experts in that field. It is coming from the people who have the counsellors. It is coming from the people who have met the adoptees. Our role is to provide the information that the legislation allows us to provide. It is not our role to decide who can receive what. Our role is to give people what the Government wants us to give people.

**CHAIR:** Thank you again for appearing today. There may be some other questions that we will write to you about, if you are happy with that.

Mrs SWINBOURNE: Fine, yes, absolutely.

CHAIR: That will form part of your evidence if you are happy to do so.

**Mrs SWINBOURNE:** Yes. If there are any other questions that you need, just write to us. The Registrar is on leave at the moment; he will be back at the end of May but anything we cannot answer we will take on notice.

(The witnesses withdrew)

(Luncheon adjournment)

MARGARET LEIGH LINDEN, Member, Family Issues Committee, Law Society of New South Wales,

JOHN CLARENCE DOBSON, President, Law Society of New South Wales, and

**JASON ANTHONY GOODE,** Member, Elder Law and Succession Committee, Law Society of New South Wales, sworn and examined:

**CHAIR:** Can you confirm that you have been issued with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses? Do you have any questions concerning these procedures.

Mr DOBSON: Yes, I have received them.

Ms LINDEN: I have received them.

Mr GOODE: I have received them.

CHAIR: And there are no questions?

Mr DOBSON: No questions, no.

**CHAIR:** Have you provided the Committee with a submission and do you want that submission to form part of your formal evidence?

Mr DOBSON: Yes, we provided it on 20 February 2013 and we wish it to form part of our submissions.

CHAIR: Would you like to make an opening statement before we commence questions.

**Mr DOBSON:** Briefly, just to thank you for the invitation for the Law Society to give evidence at this hearing. I am pleased to appear with my two colleagues who are experts in this field as well.

**Mr NICK LALICH:** Your submission notes that consent is an important consideration in determining whether the donor should be identified. Can you expand on this statement?

**Mr DOBSON:** Basically, something that has been done with consent, with the authority of that consent; otherwise you are doing it without consent and providing information not agreed to by the donor. That is basically what it is, particularly for the prior to 2010 donors who, now this law if it is retrospect, entered into that particular agreement on the basis that there would be non-disclosure.

**Mr NICK LALICH:** How would you feel if a donor consented at the beginning, when he was asked whether he would consent to all information being given to the donor conceived child, then changed his mind 10, 15 or 20 years down the track and wrote to the Registrar saying "Please give none of my information "? I am asking you as you are lawyers.

**Mr DOBSON:** I look at it more as a contract basis that it is entered into and the terms basically cannot be changed after the event has been performed.

Mr NICK LALICH: Do you feel that it has to be done as a contract? Do there have to be signatures?

**Mr DOBSON:** I look at it on the legal side. It is a contractual matter. He went into it with the full knowledge, the parties all did the same, on what the terms were and many years down the track to change your mind, that is too late.

Mr NICK LALICH: It cannot be done.

Mr DOBSON: It is like buying a car.

Mr NICK LALICH: Yes, absolutely.

CHAIR: It can be done and then it has to be tested in the courts.

**Mr GARRY EDWARDS:** The Committee has heard from stakeholders who believe that the right of a child to know their genetic heritage outweighs a donor's right to privacy. Can you comment on that?

**Mr DOBSON:** I think it is a two-way street. Basically, the right of a child is paramount but most children who are looking for this information seem to be adults now. I know my friends have a different view. My view is that the agreement you entered into at the start, with full knowledge that you were not going to be disclosed as the donor, takes paramount over that of the child. The information that you could seek, which is necessary, can be obtained without the identity of the donor being disclosed. So I do not see a difficulty in not disclosing.

**Mr GUY ZANGARI:** Some submissions have recommended a system of contact vetos, similar to the system in place for people adopted before 1990 in New South Wales, to protect the privacy of both the donors and donor conceived individuals. What is your view on contact vetos?

**Mr DOBSON:** My personal view, and from experience with people I have known in practice, particularly friends, is that there are some occasions you would not want to have contact with the particular child and vice-versa. You might not want to know if your donor was now a convicted murderer in jail, for a start. Basically, coming back to problems with donors, it is sometimes not so much that disclosure has not been made to their wife. It is the children, it seems to me, of the donor who get affected by finding they have a stepsister or stepbrother they were not aware of and finding out at an age of about 20, 24, some of them, and the repercussions for that were quite amazing to see. Although the wife knew, the children did not. So I think the right of veto should remain.

**Mr NICK LALICH:** Would you find that the children are more concerned due to inheritance rights or is it that they would not care if they found they had a couple of brothers and sisters so long as their inheritance is not going to be watered down?

**Mr DOBSON:** I think that inheritance may have had a reasonable consideration. The other particular person, who was young to me at 24, was concerned of the honesty of her father not telling her and that is a very sensitive area, where the brother did not care at all.

**CHAIR:** Some of the submissions that we have received dispute the status of confidentiality in the document signed by sperm donors, saying that they do not provide sufficient legal reason not to grant full retrospective access. Can you comment on that?

**Mr DOBSON:** I think most contracts that you enter into, if they are quite simplified in common language, are probably better than legal contracts that are hard to follow. So I think the simplest document says what it means—no contact, no communication of your details and personal information. However, as I said, that can be overcome by disclosure of the medical information. I think it still should remain, because donors were making donations on the basis of being confidential. I do not think in their wildest dreams that some of the students who I knew ever thought that, after they qualified and got admitted, they were going to be nominated as parents of particular parties.

**CHAIR:** On that, one of the key issues we are facing as a Committee in this particular inquiry, is about retrospectivity. That really is fundamental to maybe working through the problems that we are facing in relation to this particular sector, with kids or individuals who are donor-conceived. If we were to go down that path as a government and change legislation that allows retrospectivity that, I assume, would open us up for litigation and being sued, as governors, for compensation. As you said regarding the students you have had in the past who have donated, thinking their information would never be released.

**Mr DOBSON:** Yes, it is opening a Pandora's Box in other fields. We all object to retrospectivity on taxation matters, it is very dear to everyone's heart. It is changing the goal posts after the game's finished—and I think that is the paramount concern. People entered into these arrangements on the basis of anonymity and that is being changed altogether, for the views of people later on in generations with different views to the generation that was part of the donations.

**CHAIR:** Even though, later on, those generations are paying the consequences for those decisions made earlier?

**Mr DOBSON:** Well, you can say that there are consequences of it but what were the consequences? You do not have a say, when you are born, in whether you have got natural parents or donated. I do not think it makes, to me, any difference whatsoever in that nondisclosure, particularly if you have got health details, you can cover it by any health issues.

Ms LINDEN: And a veto on contact.

Mr DOBSON: Yes, and a veto on contact.

**Mr NICK LALICH:** On the donor's information, you are saying retrospectivity would be against all our principles of taxation and everything else?

Ms LINDEN: Yes.

**Mr NICK LALICH:** I think you may have answered this, but the medical records, what would be the problem in making that retrospective?

Mr DOBSON: We do not have a problem with that.

Mr NICK LALICH: You don't have a problem with that? Legally nobody would challenge that?

Mr DOBSON: No, because the anonymity is still there.

**Mr GOODE:** Can I add to that? One of our committee's issues—not particularly an issue but a concern—is that the information at the moment for people conceived with donor gametes, is that it is held by the clinics. They do not have to keep it for a particularly long period of time and that information can easily be lost unless it is all collected fairly quickly. Once it is collected, then you can figure out what needs to be done with legality and sharing that information but we do need to collect that information before it is lost.

**CHAIR:** That is a question that we have been asking because we think the record-keeping in this sector is pretty poor. It is in the hands of private clinics that can be closed down tomorrow and get taken over. We have heard of examples of information being lost or, in some cases, deliberately destroyed. There is no question that we are looking for a central register and most of us agree it should be a national register, rather than a State-by-State register.

You are right, having that information and collecting that data and making sure the integrity of that data is correct is part of it. If we go down the path of retrospectivity about releasing that type of information in the future, we need to make sure the information is correct and true. At the moment, we are in a position where we lack, I think, a sound process in collecting and maintaining data for future generations.

**Mr NICK LALICH:** Further to the question of anonymity and retrospectivity, as far as the health records go, how would you feel if you could give the donor-conceived child just the name of the father? So the guy knows, "My dad was or is John Brown" but with no address. How would you feel about that? Is that still holding anonymity?

**Mr DOBSON:** No, because it is so easy to trace and search and come back. Some people are persistent and would make inquiries in the names until they got to meet their father.

Mr NICK LALICH: You feel they could do that?

Mr DOBSON: Of course.

**Mr NICK LALICH:** With a name like John Brown or Jack Smith, you would have millions to go through but if you had a name like mine, you would probably bring it down pretty quickly.

Mr DOBSON: That's right.

Mr NICK LALICH: But if you had a name like Smith or Jones—

**Mr DOBSON:** We have got no control over names. I know my sister said the other day she would change her name to Smith and leave home so that the kids could not find her.

**Mr NICK LALICH:** My question is, some people have submitted that retrospective access to donors' information would affect the doctor-client relationship. Can you comment on this perspective?

Mr DOBSON: I cannot, I am sorry.

Ms LINDEN: The doctor—?

Mr NICK LALICH: I suppose they are saying there is a doctor-client relationship.

Mr DOBSON: I do not know whether we can answer that. That is the patient and doctor relationship.

Mr NICK LALICH: Through the clinic.

**Mr DOBSON:** Which you have as privacy, as it is. They would be the better people to talk to you on that aspect.

**CHAIR:** The question then, maybe from a legal perspective, would be where you have that client and doctor relationship and confidentiality and privacy, if we were then to bring in retrospectivity where anything is said or could be said, therefore we may be intruding on privacy issues in the future, regardless of what you say to your doctor in that office, at some time could be brought forward.

**Mr DOBSON:** Yes, That is right. It is a question, too, of what authority the Act would have to provide to get that power to go back into that area to overcome the doctor relationship—the client to patient privacy. It is treading in new fields. You could assist by promoting more work for us?

**CHAIR:** Now, now, we do not want to do that, do we? You said earlier you want to simplify the contracts, not complicate them.

Mr DOBSON: We are talking about simplification.

**Mr GARRY EDWARDS:** The Committee has received some evidence stating that the United Nations Convention on the Rights of the Child, frequently cited as providing grounds for children to access information about their parents, applies only to children not adult donor or offspring. What is your response to this?

Ms LINDEN: Could you repeat that? I missed the point.

**Mr GARRY EDWARDS:** The Committee has received some evidence stating that the United Nations Convention on the Rights of the Child, frequently cited as providing grounds the children to access information about their parents, applies only to children not adult donor offspring. What is your response to that?

Ms LINDEN: They have only got that right when they are an adult not when they are a child?

Mr GARRY EDWARDS: The other way around.

**Mr NICK LALICH:** No, they have that right when they are a child but when they become an adult they do not have the right anymore.

Ms LINDEN: It sounds very odd. I am trying to work through it.

**Mr DOBSON:** Our response that I think I read here in that regard is that the right should remain with the child even as an adult and it is only the prior to 2010 donor that would not have the right to contact the child, so it is probably contrary to that view you have just expressed. To me it would seem in practicality that the child as an adult would always be the person looking to find out their parentage, not the child when they are younger. The only need for a child when they are younger to know their parentage, et cetera, is for health reasons,

particularly if there is an illness and they need to get that information. From the experiences I have had the people who have been looking to see their parentage have all been adults.

**Ms LINDEN:** And aren't we using the word "child" in this situation as a convenient, in a sense, offspring. Whether a child is an offspring or an adult, they still have the right to know. It is not a child as in a person under 18. I think that is probably how I would see it.

**Mr GOODE:** I think our submission was in relation to the views of the child and the child having the right to get their information. Our submission was based on the situation as it is now where a donor can voluntarily lodge their details and if that child wants to find out those details they can apply and so the donor does have some rights but they cannot contact the child unless the child does make a contact with them first.

**CHAIR:** But I think the point that was being made earlier is again that the United Nations Convention talks about the rights of a child—

Mr GOODE: Yes.

**CHAIR:** We call it a child but it will eventually be an adult—we call it a donor conceived individual, for instance.

#### Ms LINDEN: Yes.

**CHAIR:** If I read your submission correctly, you still support the rights of the child in front of the donor?

Mr GOODE: Yes.

CHAIR: Your concern in this particular case is about retrospectivity rather than going forward?

Mr DOBSON: That is it.

**CHAIR:** So if we were to draw a line today going forward of all the information of what is best for the child in the future, you are comfortable with that?

Mr DOBSON: That is right.

CHAIR: But the issue around retrospectivity, going backwards, is what we are all struggling with?

Ms LINDEN: Indeed.

**Mr NICK LALICH:** So we make it just as difficult for the donor to go back and look for his children as the children to go and look for the donor?

**Ms LINDEN:** I think more difficult. That should not be the case because that person was an adult when they entered into this contract. They knew what they were doing and, as Mr Dobson said, that was a contract they entered into. They cannot change their mind because they were adults and knew what they were doing. It is the child who had no part in that process. That is why there should be a differentiation between the donor pre-2010 and the child pre-2010.

**CHAIR:** We have a small issue. We heard earlier today that there may be a loophole in the current legislation where a donor consented to all the information being provided, the couple who chose that particular donor was specific that they wanted a donor who was happy to have all the information so that the child grew up understanding who the father, however, five or six years later the donor then retracts the consent because the current laws allow for that to happen. The child now wants to know who the father is and the couple would like the child to know who the father is, yet they face obstacles because the law currently does not allow for any information because the donor has the right to rescind his consent.

Mr DOBSON: I was not aware of that but that is a legislative problem.

**CHAIR:** It is; that is right.

Mr NICK LALICH: It is a contractual problem.

**Mr GUY ZANGARI:** What are the legal differences between implementing a system which grants conditional access limited to non-identifying information or one which allows full retrospective access to identifying information?

**Mr DOBSON:** Basically one gives you the anonymity but you can get the facts of your medical history et cetera but the donor and the recipients remain anonymous and the other is everything is disclosed.

**CHAIR:** Your submission states that the Registry of Births, Deaths and Marriages should be the agency responsible—and I think most of us agree with that—for managing donor information because we are looking for a central register. There will be question marks around the skillsets, knowledge and processes needed to manage that. Do you have any comment about that?

**Mr DOBSON:** I think they have the first good leg up in having the ability to do it and then it is matter of training the staff to cover those circumstances, which is less onerous than a full new department altogether. You would need fewer staff in that area of Births, Deaths and Marriages. It would be a lot more simplified to do it through Births, Deaths and Marriages and do the extra structure than what it would to have a new department. Government-wise it is far less costly to government to use what they have got, which works very well.

**CHAIR:** We have seen examples in Victoria where it is gone from Births, Deaths and Marriages to the Ministry of Health?

Mr DOBSON: Not a good example. Victoria is not a good example.

**CHAIR:** They are reviewing their processes. They are going backwards and forwards. I think they are awaiting the response to our report.

Mr DOBSON: They are doing all sorts of things.

CHAIR: Generally we all agree that a national register would be the best way forward?

**Mr DOBSON:** You are quite right but we cannot get harmonisation or uniform legislation. You have watched COAG?

# CHAIR: Yes.

**Mr DOBSON:** I think if we start up, which is what we are doing with the national profession, other States will follow. If New South Wales moves ahead and it is the best example, the rest of the country will follow and we may end up with the national register here in New South Wales.

**Mr NICK LALICH:** What do you think of the model used in managing adoption information where there are several different agencies, both government and non-government, involved in the process of releasing information and providing counselling to adopted people and their families?

**Mr DOBSON:** On family issues, I have done the old-style adoptions. I have not had one for many years now. There are few adoptions coming through.

**Ms LINDEN:** I am in the same position. I have not done any adoptions for 30 years because there just are not any of them around; they are so limited. The Department of Community Services or—

### Mr DOBSON: DOCs.

**Ms LINDEN:** It is not that anymore, but anyway you know what we are talking about. They are involved with that, as are some of the private agencies and I think they do a pretty good job but I must say I am really not up to speed on it all. If a government agency needed to use those other agencies for the same purpose, I do not think there would be a problem with that. They have obviously got the skills because it is a big issue; it is a counselling issue—significant. I do not think there would be any problem with it

**Mr DOBSON:** I do not know whether it is relevant because adoption agencies is totally different to what we are dealing with because with adoptions we have also got the foreign adoption agencies coming out and we have got difficulties with donors overseas. With my last adoptions, which were mainly with DOCs, they were brought about by people marrying and adopting the child into the marriage. That was done fairly efficiently. I have no experience with outside agencies. The main thing that was happening in the last one is that the child still knows all three parents and you have to provide identification, photographs and contact addresses for the child. That was a totally different issue that you cannot place on this aspect of the donor and donation.

**Mr GARRY EDWARDS:** A number of submissions have made the distinction between the provision of information about donors and the issue of contact between donors and donor-conceived people. What is your view on the retrospective provision of information as opposed to contact?

**Mr DOBSON:** The information provided did not give identity and we did not have difficulties with it. For medical reasons they are saying that information should be there because it pertains to the health of the child, but identity should remain the same.

**CHAIR:** Going back to retrospectivity, if this Committee were to recommend retrospective changes to the legislation and the Government were to adopt that, what are some of the pitfalls or issues we will be facing? It is very easy for policymakers and legislators to come up with legislation but it has to be practical and we have to be able to deliver it from the perspective of the Government and the legal profession and all those involved.

**Mr DOBSON:** I think the greatest problem you are going to have, and we have already had examples since 2010, is the decrease in donors. That is the first thing. When you start making things retrospective you can use that example for a number of other issues that are probably unrelated. Certainly it will change the goalposts and people will say, "What else are they going to change in regard to the right of that child to claim against the parents' estate and have three bites of the cherry instead of two?" What financial effects will it have on families and what will be the psychological repercussions not only on the donor but his children as well? You are getting to the stage where the children are getting older. It will have far-reaching consequences if you enter that area and it will be opening new cans of worms.

**Mr GARRY EDWARDS:** This one is out of left field. Given the issues around donor conception, what would your reaction be if we said the Government should prohibit the practice?

Mr GUY ZANGARI: That is from left field.

**Mr DOBSON:** I think you will have a lot of people moving to other States for conception. I do not think you are going to stop the train now it has left the station.

Ms LINDEN: The science is there. You just have to deal with it.

Mr DOBSON: They will go elsewhere.

Ms LINDEN: They do now.

**CHAIR:** The majority of this happens in private arrangements anyway, so you are not going to stop that.

Ms LINDEN: People go overseas to get eggs or sperm because it is anonymous overseas and it is not anonymous here anymore. That is happening.

CHAIR: Are we seeing a decline in this country because of that?

**Ms LINDEN:** There has been a decline because it is now not anonymous. I think people are going in significant numbers to Spain and South Africa and places like that so that they can avoid the current law here, which says it is not anonymous. Clearly a lot of people want it to be anonymous and they are the people who are getting the donations. Basically they do not want their child to know any other parents, rightly or wrongly. I can see two sides of that argument. It is very similar to the adoption argument.

**CHAIR:** We have been on a roller-coaster ride on that and we hear from those donor-conceived individuals and no-one calls for the donor parents.

Ms LINDEN: That is the reality. You can go overseas and have it done.

CHAIR: That question was from left field. Definitely not what this inquiry is looking at.

**Mr GARRY EDWARDS:** People are going overseas because they can go through this procedure and everyone remains anonymous. As lawyers do you see that somewhere down the track we are leaving ourselves open to litigation from donor-conceived individuals?

**Mr DOBSON:** No, I cannot see that. It is such a minefield in relation to what jurisdiction you will take it on in—the United States, Thailand?

Ms LINDEN: It would be where it happened, would it not?

**Mr DOBSON:** You would have to get the evidence. One of the problems being a lawyer is the client will tell you something but you need the evidence to support what he just told you. Getting that evidence is difficult. I do not see that opening up litigation. I can see us losing people to interstate to get donors that are anonymous, and if you ban it altogether they are just going to go elsewhere. That is not going to solve the problem. Then you have to try to get their records in New South Wales when they need the medical evidence. That is why it is better to have a national system, but you are not going to have that so you might as well start off doing it in New South Wales and hopefully everyone else will follow and you may end up with a national register.

**CHAIR:** With regard to the consequences, I said this morning that there are members of Parliament here who sat in the Chamber last year when we apologised for the forced adoption policy of governments past. That was very hard. Those kids were taken away from their parents and they have no idea today who they were because the record-keeping was poor. I wonder as a member of this Committee conducting an inquiry in relation to children not knowing their identity in the future whether I will see in 40 or 50 years time a parliament in this State or this country having to apologise to donor-conceived individuals because of the processes, legislation and policy of the Government today.

This is what drives us and makes it hard for me to come up with a reason not to justify retrospective legislation at times, but at the same time I understand the importance of confidentiality. We are a little torn because of what we have already seen in having to react to situations arising from decisions by governments in the past. From a legal perspective, in relation to retrospectivity, the concern is about the donors. Fundamentally for me I am looking at the right of the donor-conceived individual. I know you touched on it earlier when you said no child has a say in their conception. We have an opportunity here to try to fix this. That is the point I am trying to make. I am still keen to look at retrospective legislation in a way but I am concerned about the minefield ahead of us.

**Mr DOBSON:** The right of the individual applies to the donor as well—that is an argument for a start—not necessarily the child who is now an adult. However, to alleviate that you could have a provision that the donor prior to 2010 could give his consent for all his information to be supplied. There could be some benefit in bringing it back in with the consent of the party who has the right to say no.

Mr NICK LALICH: That is if you could find them. They could have shifted since then.

Mr DOBSON: Yes, if you can find them. If you do not find them-

**Ms LINDEN:** I do not think it is quite the same as adoption because the Government did not say these private agencies could take children from their parents and force mothers to sign documents under pressure 24 hours after giving birth. This is a very different thing; it is a very considered thing. People have time. I do not think the adoption matter is something that the Government in a sense is responsible for because it did not make legislation saying that it could be done improperly.

CHAIR: That is a fair point.

Mr GOODE: If you collect that information that we talked about earlier then the Government would have the information in future if it was needed and it could then be accessed. Once you have that information

you can probably seek consent from all parties. It could still be kept confidential but you could seek consent to release that information.

**Mr NICK LALICH:** I am a little bit torn on the issue we have been looking at in that a donorconceived child has on his records a flag against that name held by Births, Deaths and Marriages or whatever registry Parliament decides to hold them. At the age of, say, 18 there is information sent to that person that "You have other information. If you wish to know about it we will give it to you". I spoke to the people in England last year and they will not tell the donor-conceived child anything unless they come in and ask them and they find out "I'm a donor-conceived child. I have come to the registry and I would like to know my information". They said they will then give them the information. But for us to do any flagging, to in any way let them know that, we do not do that because it could devastate their whole lives to find out they are not a normally conceived child, which today "normally conceived" can be many, many things. What is your opinion on whether you have a notation or not have a notation and just leave it to them to come and ask you?

Mr DOBSON: I prefer the latter: leave them to come and ask.

**Mr GOODE:** In our submission that is what we said, that we supported some notation when they apply for a birth certificate, not when they turn 18, and that appropriate counselling facilities be available so that when they do apply they can get that counselling and family can get that counselling so that they are better prepared to get that information.

**Mr DOBSON:** But I think what you are saying is different. You are saying that in the UK, which I think, in my personal view, is a better way, it saves the Government the necessity of flagging, because anyone with a flag on the birth certificate everyone else can see it, so there could be a stigma attached to it, and if someone is interested, provided you have got that information on record, I think that is the better procedure.

**Ms LINDEN:** So there would be two registries and you apply for your birth certificate; there is nothing on there to indicate that it would be embarrassing or difficult or anything. I mean a child might see their birth certificate at quite a young age—it goes to the school, people in the school would know. But then there is a separate register and if you want you can make an inquiry at the separate registry and see if you are on it.

Mr DOBSON: It may not need to be separate, just the same information but not printed.

**Mr GOODE:** That is how it is in Victoria: you get your birth certificate, there is no notation on the birth certificate but there is a separate sheet of paper saying there is further information, so that person can then ask and find out about that further information.

**CHAIR:** But that separate piece of paper comes with the birth certificate when you apply for a birth certificate.

Mr GOODE: Yes, it does, if you are over the age of 18.

Mr DOBSON: That is still flagging it.

Mr NICK LALICH: England just does not tell you anything.

**Mr DOBSON:** I think it is far better for the Government because the chances of mistakes in human nature is that someone will get an extra piece of paper attached to their birth certificate that is not applicable. It could be a shock.

**Mr GOODE:** It is only if they apply for the birth certificate after they are 18; that is when they get it. Before 18 you cannot get details and the parents cannot get details other than some basic genetic information, but they do not know who the donor is.

**CHAIR:** But that comes back down to the fact that the use of a birth certificate over many, many years has changed to becoming a primary piece of identification—a prime document of identification in this day and age. I do not think a birth certificate originally was designed for that purpose. So we are worried about the information that appears on a birth certificate, but in real terms it was not designed for identification; it was designed originally as a snapshot of a comment in time of something that happened. Unfortunately, we have gone beyond that and we have evolved in that we now use it as the number one primary piece of identification.

But that should not limit us. I do not think an attachment on there does lead to a stigma, because the attachment could mean anything and we are not giving away any other information.

**Mr GOODE:** Having it on a separate piece of paper then would not have any identifying information and personally I think that is the way I would prefer it to go because, as you say, the birth certificate can then be shown to anyone who they want to show it to and it does not have any identifying information on it as to the donor details or their method of birth, but the separate sheet of paper would say to them that there is further information if they need it.

**Mr NICK LALICH:** That is where England looks at it and says, "Hang on, that is where you could devastate that person". You could devastate the person who thought "This is mum and dad; these are my brothers and sisters. All of a sudden I've got 10 other brothers and sisters".

**Mr DOBSON:** And they were not told. It is normally at the time of marriage, when they are going to get married.

**CHAIR:** Research shows that we can have the heads-in-the-sand approach until it all comes up at 20 years of age or 30 years of age, but the research shows that if you can include that information as part of a child's life story from as early as two or three years of age the shock does not happen. It depends on how you look at it. If we are wanting it to be proactive and make sure that donor-conceived individuals have information available to them as part of their life story, that shock factor does not actually appear.

**Mr DOBSON:** I do not know, because if you look at bullying in schools nowadays and what kids find out and what they do with that information, which is a worldwide problem, I think you could be opening a door for that because you are being too open.

**CHAIR:** Thank you for appearing today. We as a committee might seek some other questions and write to you, if you are comfortable with that. If you could answer those questions they will form part of your evidence in the future.

#### (The witnesses withdrew)

## MIRANDA ELEANOR EVANS MONTRONE, Psychologist, The Counselling Place, sworn and examined:

**CHAIR:** I am John Barilaro, the Chair of the Law and Safety Committee. I welcome Ms Miranda Montrone. Thank you for appearing here today.

Ms MONTRONE: Thank you.

**CHAIR:** Will you confirm that you have been issued the Committee's terms of references and the information about the standing orders and if you have any questions relating to those.

Ms MONTRONE: I have.

CHAIR: Will you provide us with the capacity in which you appear here today?

**Ms MONTRONE:** I am a psychologist and family therapist. I have more than 25 years' experience in working with infertility and assisted reproduction. That includes counselling a number of people over the years, recipient couples—more lately single people—donors, and offspring, hence my submission.

**CHAIR:** Thank you very much. To conclude the formalities, have you provided the Committee with a submission?

Ms MONTRONE: I have.

**CHAIR:** Do you want the submission to form part of the evidence?

Ms MONTRONE: I do.

CHAIR: Would you like to make an opening statement?

**Ms MONTRONE:** Just briefly. So people know, I am a psychologist and relationship therapist. I have got extensive experience, probably 35 years overall. In that time, I worked for about nine years as a clinic counsellor from when I first arrived—I cannot remember the years. In the early 1990s, the clinics were not routinely counselling people going through donor insemination, as it was then. There was no oocyte donor or embryo treatment then. As the first of the counsellors at that clinic, I put forward a strong case that we should be counselling people, also as donors. Prior to the 1990s, generally clinics were not counselling. The clinics saw some people but it was not intensive counselling, and there were many donors, for example, who were counselled. In 2001 I did one day a week for a year and a half at the Royal Women's Hospital. I collated all the information about their donor program that they had since 1978. They set up a voluntary contact register in their own hospital.

They were already having people contacting some offspring, some recipient parents who were interested. That was before 2001. I gathered all that information that was available. There was a lot of information that was not available because the approach to record-keeping and the approach to information gathering has changed over the years. I also did some "trying to link", so the hospital had made a decision that they would try to contact some of the donors that the offspring were interested in. It was not that many—less than 10—but I did a lot of trying to find people. Even when there was identifying information on some of the donors, some of them could not be found, which is another aspect I mentioned in my submission. People can have an expectation that if they do get the name that they will find this person. I do not know that that is the case. There could be all sorts of reasons. I also have a lot of knowledge of the research evidence, which I think is very important. Sorry, I hope I am not going on too long.

#### CHAIR: No, it is fine.

**Ms MONTRONE:** There has been some very good research. Psychologists understand and take it as a basic premise that the maxim of one swallow does not make a summer. Because one person or 10 people say something does not mean that it is representative of a whole cohort of people. I am absolutely in favour of openness. I have been fighting for it since the early 90s. In 1992, the first ever paper I gave to the Fertility Society of Australia was called *Secrets in Families*, about the implications. My point is that some people have been open with their children; the very large majority probably have not. This is a very important factor if you

are talking about contacting siblings or half genetic siblings. When you do the research, there is a not good response rate from people who have used donors. People who say they are going to disclose often do not.

There was a European study, and a very, very good European study—it is probably the best study in the area, very comprehensive—where they tracked a whole cohort of people from several groups: naturally conceived, IVF, et cetera, and donor. The response rate for the donor was way lower than the others. When they tracked those children at the age of 11, 12, people who had said when the children were younger—four to eight—that they were going to disclose at the age of 11 to 12, only two out of 37 families had disclosed to their children. What I am saying is, yes, while I am 100 per cent in favour of openness and 100 per cent in favour of the Act and fought to get the recent Act in, we have to be very careful about talking about going in the past. That is my point. That was a lecture. Sorry.

**CHAIR:** That is a fair call.

**Mr NICK LALICH:** Before we start, I will ask a quick question. Miranda, you mentioned that in your research you did a comprehensive search for donors and that you could not find them, no matter how intense it was. Did you find that was because they have moved, they have changed their name?

**Ms MONTRONE:** Who knows? One fellow had a not particularly common name. There were 54 in his name on the New South Wales electoral register alone. It was not a big number. There is a lot of anecdotal stuff. Different staff members had been there since the very beginning. A couple of the staff members thought that he had moved overseas. I did not write to all 54 members on the register. Another fellow had a really unusual name. I spent hours on the internet. It was a very unusual name. No hide nor hair—nothing. I spent hours on the internet searching, checked on the electoral role, under multiple things. It would require getting information from births, deaths and marriages about marriages. Maybe his name had changed after a marriage or a divorce, or something. Or maybe he did not say the right name at the beginning.

**CHAIR:** It could have been false.

**Ms MONTRONE:** Yes. This was an era when people did not provide identification when giving donor sperm. It is primarily donor sperm. The history of donor oocytes is much more open and transparent and it has been run with the protocols used now.

CHAIR: When did you do your research?

Ms MONTRONE: In 2001.

CHAIR: When was the European research done?

**Ms MONTRONE:** My research was just me searching. The first stage of the European research was published in 1996 when the children were aged from four to eight. There were 111 families involving natural contraception, IVF and donor insemination from four countries—the United Kingdom, The Netherlands, Italy and Spain. It was a very good study. The head researcher was Susan Golombok, who did fabulous work. A team at Cambridge University continues to do thorough research.

CHAIR: That was in 1996 and you did your personal research in 2001.

Ms MONTRONE: Yes.

**CHAIR:** The stigma attached to donations has changed since then. It is much more open and transparent. Do you believe that people have changed? You said that the majority of donors were not happy to have their information released. Has that changed in the past 10 to 15 years?

**Ms MONTRONE:** For 15 years it has been clear that there would be a donor register at some stage. People like me who did counselling advised people that there would be a register; everybody has been aware of it. However, recent New Zealand research has revealed that people say they are going to say something but it is easy not to say anything about donor eggs.

**CHAIR:** Would you have a problem with legislation that forces donors to provide all of their information and that that information be made available to a donor conceived individual—

# Ms MONTRONE: At 18?

CHAIR: Yes-versus retrospectivity?

**Ms MONTRONE:** That has existed since 2010. The people using donors are good people. They just really want a child and they have been through hell to get one.

**CHAIR:** During a previous inquiry we spoke to a psychologist or a psychiatrist who said that if you make it part of a child's life story from an early age there is no real issue.

Ms MONTRONE: Absolutely.

CHAIR: I thought I heard you say that they should not be told until they are 18.

Ms MONTRONE: No, you tell them when they are little.

CHAIR: You are comfortable with that?

**Ms MONTRONE:** We tell people to practice on their children when they are changing a nappy. They could say, "Mummy and Daddy could not have a baby and this is what we had to do."

**CHAIR:** It becomes their life story.

**Ms MONTRONE:** Yes. Some interesting research has been done in this area. It involved a small group, so it is not such a well-controlled study. It was found that offspring who have always known are much more settled and comfortable with their donor or surrogacy history. If they find out in their teens it is a really bad time. I do not want them to find out at 18.

**Mr GARRY EDWARDS:** You mentioned that you had written to many of these people and that you could not find a large number. Was there any indication that you could contact them? If not, did any of them contact you irate about your blowing their cover?

**Ms MONTRONE:** Not many. About 10 offspring wanted contact with their donors. I made a decision not to write to all 54 people because I did not have any more information. The letter might say that the donor had treatment at a hospital under a particular doctor and we have further information that might be of interest to them. It might say that the information does not relate to anything life threatening but it might be of interest and if so they could make contact. The letter would be very general and if someone else opened it it would not give anything away. Often the donors have not said anything.

**Mr GUY ZANGARI:** Thank you for your submission. You state that you are not in favour of retrospective access to identifying information. Do you have an opinion on conditional retrospective access, for example, both parties needing to agree to the release of the information or only non-identifying details?

**Ms MONTRONE:** I think non-identifying details should be released early. People using donors now get a lot of non-identifying information and I am very much in favour of that. In terms of retrospectivity, I am in favour of having a voluntary contact register. There is one that is part of the central register at NSW Health, but it is not separate. I would like the voluntary contact register separate, but all of the donor identifying that exists now should be included. It could be lost—clinics close and doctors retire. I would like it all on the register now so that it is kept safe. Then, if any of the parties wish to have contact, they can advise the register and their wishes will be noted. If one donor offspring says they would like to contact the donor or a donor sibling, there can be contact.

**Ms MONTRONE:** I am very keen for all the information from clinics because I am already aware there have been at least two doctors who have retired who did a lot of donor work early on.

CHAIR: We have heard from previous inquiries about when data is either lost or deliberately destroyed.

Mr GUY ZANGARI: It was stored in a garage.

Ms MONTRONE: Exactly.

CHAIR: We are all in favour of a central register or, more importantly, a national register.

Ms MONTRONE: A national one would be wonderful but let us start with the State.

**Mr NICK LALICH:** You said in your submission that in your experience it was not uncommon for infertile patients to resist implications offered for counselling before they receive their fertility treatment. Will you expand on that point?

**Ms MONTRONE:** The doctors started referring to the counsellor, in my case me, and now it is routine practice for people to see a counsellor. Sometimes the doctors would say, "You have just got to get past Miranda first"—fantastic. Also it was a rubber stamp for some of the patients. They did not want to talk about it. They did not want to be there. They actually found it a bit of a pain. Some of them complained. I had a lollypop doll to try to bring the future child into the room because people can feel so overwhelmed by their own emotional pain at their infertility that it is hard for them to conceive. They cannot bear to hope that it will happen so they cannot think ahead to the needs of the child in the future of having some sort of information about their contact with their genetic donor.

I had a lollypop doll in the room and a number of potential recipients parents who complained about it, complained about me, and I was not mean, horrible but I was just making sure that they were aware that this is lifelong we are talking. You are talking about the future parent of your future grandchildren, we are talking here. A lot of people would say things like, "Oh but look if we make love during the month, you never know it might be my husband's baby", and things like that. For a lot of people, it is their way of settling with it. It is really quite a huge thing if you think donor sperm. The only way you could actually conceive a child from another man's sperm, other than through treatment—other than turkey-based at home which some people did—was through sex with that person. This is very much hard-wired into our psyche about the implications and people did not want to think about it. It has shift forward now.

**CHAIR:** Is counselling still a rubber stamp process today?

**Ms MONTRONE:** No, less so. It is still required protocol. I have gotten good at it so people understand I am very much on their side and realise where they are at but I am also tough. I still, even though I am private practice, see people referred by some clinics who are planning to go overseas to get donor eggs and they are really nice people. They are educated, intelligent, caring people, sometimes they are going to have to pay a lot of money when they go overseas and for some of them the idea of the anonymity has not even bothered them. They say, "It's okay, the donor is anonymous." I say, "What do you think that might mean for your child when they are 18?"

**CHAIR:** Is your counselling to bring awareness about what they are entering, not to tell them that you do not think they are suitable?

Ms MONTRONE: No. They do not think that now.

CHAIR: It is just about bringing awareness of all the issues.

**Ms MONTRONE:** It is implications and decision-making counselling. It is about them understanding the implications for themselves and for the long-term future. When I raise the issues now, most people do understand and think about it but some of them say, "We are okay if it is anonymous." They are good people.

**Mr GARRY EDWARDS:** Is there a majority reaction in relation to the anonymity aspect when you say to people, "What about the child?" "What impact will that have on the kid?" Do most people react the same way?

**Ms MONTRONE:** There is more awareness now than there used to be. This is the retrospectivity act. No, there is more awareness now and people are open to it and understand but I still think there would be a very large number of people that may or may not tell which is actually quite foolish because of the increase in knowledge of genetics. It is, as you say, much, much easier if it is just done as part of the story at the beginning. It just works fine. In relation to retrospectivity so that the cohort of people who want contact with people from very much the past, it was heterosexual couples then—treatment of single women and lesbians was not done at that time—and they would say, "So, you mean we have to tell them who the real father is?" I would say, "No." The words "real father" would be said and I would never say it.

I would say, "No, you are their father, you are the real father, you are the one that changes their dirty nappy, you are the one who takes them football" etcetera. Half their genetic information is this other person, this donor. But even then sometimes they would say, like if it was donor oocytes, which was maybe 10 years after so in the mid-1900s was when they started doing donor oocytes and that was usually known, there were some unknown, but people still would say things like, "It sort of changes when it is in me. It gets a bit of me in me." Whilst there is some recent science that shows there is a tiny bit of it true, but a large majority, no.

**CHAIR:** Twenty years ago it was between a man and woman and therefore it was easy to hide the story that your child was not your child or the father was not the father.

#### Ms MONTRONE: Absolutely.

**CHAIR:** In this day and age we are looking at the issue around same-sex relationships, lesbian couples and in those relationships the story cannot be hidden from the child that there was a father at some point. Does that change the environment in relation to information going forward? Children will want this information because they know from school and from their environment that something is not the norm.

**Ms MONTRONE:** Yes, they do. It is different. Lesbian couples and single women do tend to tell their children of their donor story much earlier on and much more often than the heterosexual couple because it is quite easy not to say.

**Mr GUY ZANGARI:** You referred to an individual or a couple going overseas to get the egg or to seek sperm donation. Has there been an increase in that occurring by residents in New South Wales or in Australia? You said the response was that it was the anonymity and they brushed off what is happening with the donor-conceived child eventually.

**Ms MONTRONE:** I cannot say whether there has been an increase. I am in private practice and I do not have a clinic connection. I have not since 2001. Some clinics like to refer people for different reasons to an outside person on occasion. They do not choose to go overseas because it is anonymous, it is usually donor oocytes and the reason they are going overseas is it is very hard to find them here. If , for example, one goes to the United States of America there are more donor oocytes available because it is commercial donation, and the donors get paid quite significant amounts. There are eggs available overseas.

Mr GUY ZANGARI: I was concerned about what you said.

**Ms MONTRONE:** Not huge numbers, no. My guess from an outside person would be that most egg donation, because it is a lot more complicated for the person to actually produce the eggs than it is for a man to produce the sperm, they know each other's identity. There may be connections or they may have met up through the Internet or something like that here. But I do not think it is a huge number because it costs too much, it is really expensive.

CHAIR: Do people who make private arrangements seek counselling?

Ms MONTRONE: People who just decide they are going to use a turkey baster?

CHAIR: Yes?

Ms MONTRONE: Probably not.

**CHAIR:** You do not have people say they are thinking about it and just need some professional advice?

Ms MONTRONE: I do a lot of surrogacy work. Yes, I have had people who are going to make private arrangements, yes, but not a lot.

CHAIR: We know there are a lot of private arrangements in relation to donors—

Ms MONTRONE: They do not come and see me, no.

**Mr GARRY EDWARDS:** You expressed support for a voluntary donor register such as that currently maintained by the Ministry of Health. In your view is the current voluntary register sufficient?

**Ms MONTRONE:** No, because I want all of the clinic information with regard to the donors and the recipients to go on the register—you know the ones that are stored in garages or some of the clinics still have. I think it needs to be really safe. I have nothing in particular against the Department of Health but I would prefer it to be in Births, Deaths and Marriages because that is their job.

CHAIR: Do you think the voluntary register has been effective so far in obtaining donor information?

**Ms MONTRONE:** I do not know how it is working at all. They did actually speak at a meeting that I was at and I was really surprised that they were not aware that the Royal Hospital for Women had an up and running donor voluntary contact register that they had established since 2002.

CHAIR: So we are not doing a good job of publicising the register?

**Ms MONTRONE:** I do not know. I do not think its ads; I do not know what it is. I am sorry, you have just made me think. You asked about whether I had irate people contacting me like donors and I did not answer. At the hospital I had a few, no more than 10, donors contact me because they had heard about it and they wanted to know the position. Of that few, a couple said they wanted to know how many offspring they had—that could have been a bit scary. Now it is limited, but it could have been a bit scary because for some of the offspring there was a fair few. I had a couple, maybe a few, but they weren't irate; they were scared, if I had to pick a word, as in: What did I do when I was young? What has it meant now?

**Mr GUY ZANGARI:** You note in your submission that sometimes donor information may not be able to be located or important information may have been destroyed. Will you expand on that?

**Ms MONTRONE:** I have talked a bit about not being able to find donors. I am also aware that there was some information removed—some of the names and identifying information was removed. I think the person who did it probably regretted it but he felt obligated, that he had a moral obligation to the donors in that he had guaranteed them anonymity. I do not know; I was told by someone else—he did not talk about it with me in detail. I did not see him do it or anything but it was, they were cut—the information that I was using was cut off. It was a very, very different world in the 1980s. It is very hard when you look back with the morals, values and processes and the transparency and stuff of today; it was a very different world.

CHAIR: You deal with a number of clinics, do you not?

Ms MONTRONE: I am an external practitioner.

CHAIR: Have you seen a lot of clinics close or change ownership?

**Ms MONTRONE:** At least two that I know of did. There was a doctor called David Macourt who had a big practice at Hurstville and my understanding is that another doctor: Anne Clark has his records, but I do not know for sure. He retired—I do not know for sure. Dr Trevor Johnson did a lot of very early work with single women and he had a very extensive donor bank. I am pretty sure he is retired, though I think that clinic was taken over. It is not that the clinics are not professional; it is just that it is an ephemeral thing when it moves from clinic to clinic and it is not top priority. That is why I want it in the public record.

**Mr GUY ZANGARI:** The Committee heard evidence last year from a donor-conceived individual who showed us the records from the hospital and the information that had actually been cut out.

Ms MONTRONE: Yes, it was cut.

Mr GUY ZANGARI: To that particular individual it was devastating.

**Ms MONTRONE:** Yes, I know; it was. It is very hard to find that out but when I say that I was like we did do some donor linking. Some of the information was not cut out, so I do not quite know what was decided and what was not decided.

Mr GUY ZANGARI: You are correct that it was during the 1980s that this type of practise occurred.

**Ms MONTRONE:** It was also too—and this was not the hospital where it happened—but in about 1985 I think there was a big donor program at Westmead—that was also the AIDS time. There were gay men who donated, men who could not have children—maybe this was their way, I do not know. The donors had no counselling so any discussion about why they did it, what they did and who they were is totally hypothetical and a lot of anecdotal stuff—people said this, people said that. I wasn't working in the clinic then but at Westmead there was actually a case where a guy who did not know he had AIDS had donated and several women died from AIDS because of that donation. So that was all happening in the 1980s. So it was a very scary time for a lot of people, disturbing.

**Mr NICK LALICH:** You commented that in your view the management of the ART central register is inadequate due to the guidelines under which the register was established. Can you expand on this point? What are the limitations of the guidelines?

**Ms MONTRONE:** I think the register is okay. The central register that is there now I do not have a problem with but it is the retrospective stuff—the voluntary contact information. It is pre-Act information that I am interested in and I am really thrilled that you have got this inquiry because that needs to be addressed.

**Mr NICK LALICH:** You mentioned doctors that you did not know whether or not they were retired, the Committee has had information that there was a doctor that had all his files on these donor-conceived children stored in his garage.

Ms MONTRONE: Quite possibly.

**Mr NICK LALICH:** Do you think there should be legislation to ask them, and in a way force them, to give that information to the central register?

**Ms MONTRONE:** Yes, that is what I want you to do. I do not know but my understanding is that the central register is only from the Act on, so it is put into another register.

**CHAIR:** It is only part of the conversation by forcing clinics and everyone else who has information to provide that information to go into a central register, the other part of the conversation is if we release that information in the future?

Ms MONTRONE: That is right. I want the information kept because 50 years from now—

CHAIR: Good point.

**Ms MONTRONE:** I do not know that you would have to force people. I think the clinics would be quite happy to hand the information over.

**CHAIR:** I am not convinced of that. We keep writing to clinics to make submissions and to attend this inquiry and there seems to be a veil of secrecy at the moment. They are not forthcoming and it feels as if we need to continually apply pressure for information. I may not agree with you there.

**Ms MONTRONE:** It is said anecdotally that many of the donors were medical students, so they were of that era—I have heard stories that they were. Some hospitals would say things like—they were told in the third year medicine course: "We need sperm, go over and donate." and they would donate. My sister actually reminded me—I had forgotten—of my telling her about my friends when I was at university who would get \$10 for a donation. They would go and donate. There was no thought or consideration of the implications; it was just the culture of the time. In fact, some writing at the time said it was just like blood—it patently is not just like blood. It is said that they were mainly medical students, so they may have been medical students. One of the people who contacted me at the hospital was a doctor but he wasn't like all of them. In fact, the Royal Hospital for Women had obtained a lot of their donors from connections to the blood bank—I think they had brochures at the blood bank—so they asked people who donated blood to come. I do know from the information I had that

there wasn't a lot of medical people and also there was some information missing—I am sorry that was very rambling. The belief that they were all doctors maybe why there is this sort of culture of silence around it by the clinics—not necessarily that those doctors at the clinics think that their colleagues donated but they maybe implicitly protecting, who knows—but I think part of them would like to get rid of the data.

**Mr GARRY EDWARDS:** In terms of your professional experience, who have you mainly dealt with regarding donor conception issues? Have you had much experience with donors who are dealing with the repercussions of their past donations?

**Ms MONTRONE:** No to the end. I have mostly dealt with recipients, potential parents; some dealing with offspring and their parents, and some linking offspring, very small, under 10, and some contact with donors but mostly, very largely, with potential parents.

**CHAIR:** You mentioned the need for letterboxing, as has been undertaken by VARTA and some individual clinics. Is this something you are aware of is currently happening?

**Ms MONTRONE:** Yes, at the Royal Hospital for Women. It was one of the things I set up, helped set up. It was already sort of happening informally. We set it up as a particular formal protocol in 2001, so they have a formal protocol about how they do what they do, very much the same sort of guidelines as the current ANZICA, which are the infertility counsellors association donor linking guidelines.

**Mr GUY ZANGARI:** With regard to funding counselling for donor conceived individuals, can you identify which issues you believe it should be limited to and are you aware of any current government-funded programs that would enable donor conceived people to access this type of counselling?

**Ms MONTRONE:** Answer the second question first, it was mentioned in the discussion paper the potential for mental health plans. I do not see that they will be because mental health plans are for diagnosed mental health problems. It does not mean that every donor offspring, or donor or recipient or parent will have a mental health problem. No, there are no funding programs that I know of. I do not know where a place like the post-adoption centre, which is run for adoption, gets its funding. Probably State Government or Federal Government. There is no funding that I know of.

**Mr NICK LALICH:** You said that the BDM already has in place limitations on access to personal data such as births and marriage data for a time limited period of many years. Can you clarify what these limitations are?

**Ms MONTRONE:** I am not 100 per cent sure but I think it is 45 or 50 years that you cannot get information like current birth records information. I do not think you can get it as a random person. When I was trying to chase up for one of the donors I was trying to find, I was trying to find marriage records and I cannot get access to them in that period. So they have a period—I think you can get historical data. I think people like the Red Cross have a searching process that they can do it. The hospital did not go to that next step of using the Red Cross special searching process where they somehow can get access to more current information. I do not know the actual limitations, I am sorry.

**Mr GARRY EDWARDS:** The Committee has heard evidence from you and others that some donor's attitudes towards the release of donor information may have changed over time. Are you aware of any studies or research indicating such a change?

**Ms MONTRONE:** Only one study done by Ken Daniels in New Zealand. He is from New Zealand but he was connected to England, I think, and it was a small number of donors they contacted. It was like, "Would you still donate" if they had donated in the past. Some of them had changed their minds. They donated under condition of anonymity and they were still interested more in, "Would you still donate even if you were aware that you were going to be identity release". I do not remember the exact percentage but it is a very small study; it is like 45 people, if I am picking off the top of my head. It is not a big study. There is not a lot known about donors. Their point of view, I can bet—I do not have to ask—though you might have an individual donor submission but you do not have a submission from a group representing a large number of donors. The DC group is fabulous but it is not like it has lots and lots of donors as members. It is mostly parents, recipient parents or offspring who are members. The donor's voice is quite silent. It is a scary thought. **CHAIR:** A number of submissions have made the distinction between the provision of information to donors and the issue of contact between donors and donor conceived individuals. What is your view on the retrospective provision of information as opposed to contact?

#### Ms MONTRONE: Providing non-identifying information?

CHAIR: I think my question is a bit wider.

Ms MONTRONE: Like a contact veto?

CHAIR: Yes.

**Ms MONTRONE:** I do not know. I have thought about this. I do not know how it works in adoption. If I really wanted to meet someone and I knew their name and their address, I would definitely drive by their house; I would definitely Google them.

CHAIR: In this day and age of social media.

**Ms MONTRONE:** I do not know how a contact veto works. It would be really hard. Without saying I would be a stalker, it would be very hard not to find out if I really wanted to meet someone. And people really want to meet someone. It would be hard not to go further, just accidentally bump into them somewhere.

CHAIR: I think everyone with Facebook is a stalker in this day and age.

Ms MONTRONE: I do not know but it would be really hard.

**Mr GARRY EDWARDS:** Can you give us some examples of the issues covered during counselling for donors, recipients and donor conceived people?

**Ms MONTRONE:** Sure. The counselling is routinely done with the donors now and the recipients. The donor conceived is not routinely done because they are not around. For example, if you seeing a donor—it is known donation; I have never worked at a clinic where they recruited anonymous identity release donors. I have seen some known donors of sperm but it has mostly been known oocyte donors. The counselling is about the implications for them and their children and the implications for the recipients and their families, because they have grandparents, aunts, uncles, brothers, sisters, and the implications for the potential offspring. So what does that mean in terms of them and who will know and what will they know?

When you do the implications counselling with the recipients they all say, "Yes, of course, we will tell, absolutely, whatever you say Sir." And I think when they have their baby it is like, "Oh, we'll put that in the hard basket." The implications are the implications generally about it from the point of view of them as a family and their future family, and the implications for their child and what does it mean not knowing and—this is the family therapist in me—what does in mean in communication in family members where one person has an implicit, more stronger right, because they are the genetic mother or the genetic father as well as the social father and the other person has an implicit—like if you have an argument about something, what does it mean in the relationship?

Parents, when the child does something wrong, will say, "It's your son" or "It's your daughter". They will look at each other and say it that way. That has an added layer when there are no genetics there. When the child does something obnoxious when they are a teenager it is very easy to say "That's because of the donor" in their head. If you have not told them by that stage it is a very bad time to say something. But maybe you are saying to yourself that the reason the child is doing all this obnoxious behaviour is because of the donor. It interferes with communication. It interferes with parenting. As was brought up before, if you just say it from the beginning it is like part of the story.

**CHAIR:** In relation to implication counselling, you said people come in and they just want to have a baby so they say yes to everything. Have you ever had a donor back out after counselling, saying "Hang on, this is a bit more than what I thought"?

**Ms MONTRONE:** Remember I have mostly done known donor counselling. I have, yes, as in "Oh, I had not really thought of this" but not a lot. They do a lot of talking before they come to counselling. I have not

had recipients back out. I have had donors back out, as in "Oh, um, really, yes, of course, you asked a question I had not thought of."

CHAIR: Is there anything else you would like to finish off?

Ms MONTRONE: No, that is lovely.

**CHAIR:** We may write to you with further questions and if you are happy with that and those responses will form part of your evidence today, if you are happy with that.

Ms MONTRONE: Thank you for the opportunity.

# (The witness withdrew)

**CHAIR:** I welcome Elizabeth Hurrell and Professor Mark Bowman to today's inquiry. Can you please confirm that you have been issued with the Committee's terms of reference and information about the standing orders that relate to examination of witnesses and do you have any questions concerning these procedures?

Ms HURRELL: I have.

Associate Professor BOWMAN: Yes and no concerns.

ELIZABETH MAVIS HURRELL, Representative, Fertility Society of Australia, and

MARK CHRISTIAN BOWMAN, President, Fertility Society of Australia, affirmed and examined:

CHAIR: Can you please tell us in what capacity you are appearing before the Committee today?

Associate Professor BOWMAN: My name is Mark Bowman. I am here primarily as the President of the Fertility Society of Australia. I am also a gynaecologist and fertility specialist.

**Ms HURRELL:** I am Elizabeth Hurrell. I am here as a representative of the Fertility Society of Australia. I am the counsellor representative on the Fertility Society Board.

**CHAIR:** Have you provided the Committee with a submission and do you want that submission to form part of the formal evidence?

## Associate Professor BOWMAN: Yes and yes.

CHAIR: Would you like to make an opening statement before we commence questions?

Associate Professor BOWMAN: The statement we would open with is effectively contained in the executive summary of the submission. That was that, firstly: The Fertility Society of Australia [FSA] is the peak industry group, if you like, with relation to fertility management and treatment in Australia. It consists of medical practitioners, counsellors, nurses and scientists. We have no formal legislative role but I guess in the two decades that the FSA has been constituted, it has generally been the central focus of really both societal management of infertility, medical and paramedical management of infertility. Its members are the people who have looked after our clients, the people that these issues now pertain to and we have had a strong role in developing what we believe are appropriate policies for management, particularly in these rather complicated areas. That, we believe, is our reason for being able to make fairly informed comment and feedback to you today.

In terms of the specific issues with regarding retrospectivity and donor identification, we recognise that today, in the modern era and in fact now governed by New South Wales law, that there is no longer such a thing as anonymity. Whether that is because donors and recipients are meeting prior to treatment commencing or whether that is being facilitated by the clinic, nonetheless the details, as you know, are recorded. So the challenge, as we all know and that is why we are here, is what happens with regard to information where donors have operated in the past in an episode of what they perceived and still perceive to be anonymity and yet we have the adult recipients of donor conceptions wishing to trace their origins. So we support the right of people to be able to know their origins.

However, we recognise that there is a fundamental problem with retrospective divulging of information because that, to us, is untenable because we also, in a sense, managed the donors at the time, or my forebears did, and in good faith those individuals—particularly we are talking here about sperm donors as it leads back—were given information, in good faith, that their details would not be divulged in the future. So, it is our strong view that it would be untenable, against their consent, to go and release that information. Nonetheless, we do believe that there are measures that, whilst they may not be perfect and whilst they may not provide the information that everybody wants, there are mechanisms that already exist within our protocols and guidelines and which are already operative in other states and indeed within individual units, whereby donor linking, if you want to call it that, is a reasonable and viable option. We are happy to help provide advice about those things. But that is, I guess, the short summary of the executive summary.

30

**CHAIR:** A quick question that is not part of the formal questions here. We heard from a witness earlier, a lesbian couple that have had a child and when they were out looking for donors at the time they were looking for specific donors who were happy for their information to be forwarded to the child so that the child grew up with that information. That was the agreement they entered into. They only had a small selection of donors because a lot of donors did not want their information given but there was consent from the donor that that information could be forwarded. Five or six years down the track and the donor has retracted that consent. It brings me to the question of the type of agreement that clinics enter into with donors and how that actually works or does not work. Does it come under contract law? Is there a legal standing for that couple to seek compensation?

**Ms HURRELL:** If that couple entered into that arrangement pre-2010, my advice as a counsellor would have been that the right to information was not a legal right for either that couple or a donor to see a child at that point in time. Even though there might have been an understanding with the clinic, and I cannot comment depending on the clinic, that the donor was willing to be known, that was never a legal right and the donor would have had the opportunity, in a sense, to change his mind. It is very difficult because different clinics operate in slightly different ways, so it is very difficult to comment in less broad details.

**CHAIR:** Because we have not had clinics come to the hearing or make submissions independently, the type of agreements actually in place, what are the written agreements, the contracts, that people sign? Are they different from clinic to clinic or is there a standard agreement?

Associate Professor BOWMAN: There isn't a standard form. It certainly is not a legal contract per se, it is a consent form with associated information. And yes, it does vary. Units do not use the same words. I think the general concepts are the same across different units. They all have their different take on how to do it but the fundamentals of what they are saying are fairly similar. I suspect there probably would be potentially different wording with regard to that scenario.

**CHAIR:** As you rightly say, there was no legal requirement at the time but you can understand that now this family, both the donor-conceived individual and the parents there, their whole world has changed because they thought they had entered into an agreement that allowed the child to progress through life with full knowledge of all the information. That has changed now. That concerns me that that can happen but that is a loophole within the legislation and the law.

**Ms HURRELL:** I can only comment specifically that the clinic setting that I worked in pre-2010 clearly stated on the consent that there was not such a right. That is a specific comment and does not pertain to the whole picture.

Associate Professor BOWMAN: Our concerns are not springing necessarily from that situation. Our concerns are of the very long-term scenarios where it was the opposite, it was perceived to be an effective guarantee of anonymity.

**Mr NICK LALICH:** Following on from the Chairman's question about legal and contractual rights, do you think we should make the contract a binding one so that the donor has to abide by it and he cannot do what happened in the case referred to where he remarried a few years later and decided he did not want his information given out? Those people were devastated that they could not tell their child. From your experience, do you think we should legislate to make it contractually binding?

**Ms HURRELL:** Donors cannot do that now as a result of the Assisted Reproductive Technology Act coming in. Again, our consents clearly state that they will be identified to a donor-conceived person when that person is 18 years of age. If a parent wants that information disclosed when the child is eight years of age that will not be the case. Clearly now that right exists at 18 years of age.

Mr NICK LALICH: So it is a legal document—they cannot pull out of it now?

Ms HURRELL: Yes, now, under the umbrella of the ART Act.

**CHAIR:** Mr Lalich is alluding to the fact that we have heard from psychologists about the importance of a child knowing their life story as early as two or three years of age. But if a donor agreed today that that information should be forthcoming, should we make that a contractual agreement that is binding by law so that they cannot reverse their decision or rescind their decision in the future?

Associate Professor BOWMAN: The regulatory or best practice that surrounds all of this is not just measured in legal instruments. If proper and appropriate counselling has occurred prospectively and there is evidence of that and it is in association with the consenting process, I suspect that very much binds the donor anyway. It is a question then of whether you would run a case-precedent approach as opposed to trying to retrospectively write it into the legislation. Completely off the top of my head, I think most of us would be fairly sensitive to the needs of the particular recipient couple and the child. I would also be concerned that appropriate counselling happened at the time.

CHAIR: Of course.

Ms HURRELL: I am not clear whether that particular couple expected contact when the child was 18 or earlier.

CHAIR: No, early on, from day one.

Associate Professor BOWMAN: Then there are two separate issues: one is the age of the child at contact and the other is the withdrawal of consent for knowledge at any stage. I think it is the latter that is the bigger issue.

**Mr NICK LALICH:** You state in your submission that the introduction of retrospective legislation would violate agreements entered into between doctor and donor. Can you clarify the status of these agreements? For example, were they made with the doctor or the clinic? Do you have an example of such an agreement that you could show the Committee?

**Ms HURRELL:** It would have been a contractual agreement. The donor would have agreed to consent to use of his donation under certain conditions and with an understanding that that donation would be an anonymous donation. It would have been a medical contractual agreement with the doctor in the context of the clinic.

Associate Professor BOWMAN: Some of the clinics were a private clinic, effectively one doctor, and some of them were hospital-based clinics such as ours at Royal Prince Alfred Hospital where the doctor was the agent of the clinic, I suppose, but ultimately it was via a medical consultation.

Mr NICK LALICH: Following on from that, when a donor gives a sample or whatever you call it—

Ms HURRELL: A donation.

**Mr NICK LALICH:** —you would not use all the sperm involved. Could a doctor then impregnate 10 different women without the donor knowing he has used it or would you use the whole donation on one person?

Associate Professor BOWMAN: Firstly, one sample is often cut down into multiple smaller samples which are then frozen, and the donor might return up to six times to contribute more so you might end up with 100 straws and perhaps two to three straws might be used per treatment cycle. Then the sperm is frozen and quarantined. That has been the case since the early 1980s. Subsequently, under the old anonymous paradigm, the clinic then used those straws for up to a set number of recipient couples.

Mr NICK LALICH: They would not have to notify the donor of that?

Associate Professor BOWMAN: No.

Mr NICK LALICH: He would never know that he had conceived another 10 children?

**Ms HURRELL:** My understanding of past practice is that there would have been some discussion with the donor that his donation would be used for multiple families. Previously the code of practice of the Fertility Society that pertained—I cannot give you the exact years—was that donors should be used for up to 10 families. Our legislation now says for up to five families. Those things would have been part of the discussion with the donor, that their donation would have been used for multiple families.

**CHAIR:** Part of Mr Lalich's question was about an example of such an agreement. If we are talking about standardising agreements or contracts in the future is there a chance for the Committee to get a copy of an agreement?

**Ms HURRELL:** Within the context of my clinic, the Department of Andrology at Concord Hospital was the clinic that recruited donors. I could approach the head of that department and ask him to provide an example.

**Associate Professor BOWMAN:** It might be there are examples persisting or de-identified examples of the original agreements in the completely anonymous paradigm, transitory and then post—

**CHAIR:** That would be fantastic if it is possible.

**Mr GARRY EDWARDS:** The Committee has heard evidence of the importance of confidentiality and faith in the doctor-patient relationship. In relation to gamete donations, is the donor considered a patient in the same way that the person receiving fertility treatment is?

**Ms HURRELL:** Obviously the donor does not have a fertility problem whereas the recipients do have a fertility issue, so there is that subtle difference. But there are still the principles of a doctor-patient relationship governing both.

Associate Professor BOWMAN: There is because there is a history and examination taken. The issues here are around a person's private information and in that sense—this is the difficulty, is it not—there is a tension. Both have a right of private information. In that sense you would argue the relationship established between the medical person and the donor is almost analogous with that established with the recipients. That is the difficulty we have. The majority of members of our society are interested in the very important needs of donor-conceived individuals. It is just that we are also very concerned about the needs of the original donors. It is not that we are in one camp. The challenge is that the donors by their very desire to maintain their anonymity are the ones who do not have a voice.. This comes from a time when donors were young individuals, often university students, some of them legal students some of them medical students, and some of them have probably ended up in fairly high parts of society and are quite interested in maintaining their anonymity. That is one of the challenges

CHAIR: Members of Parliament maybe.

Mr GARRY EDWARDS: It pretty much sounds like the answer is yes.

#### Associate Professor BOWMAN: Yes.

**Mr GUY ZANGARI:** You support the outreach to donors by clinics in a sensitive manner. What has been your experience of this and what has it involved?

Associate Professor BOWMAN: There are a number of different models you can do it under. Ms Hurrell and I work together at Royal Prince Alfred Hospital where on the recipients' side there is certainly no shortage of desire and we have tried to introduce donor linkage in specific cases. It is usually but not always driven primarily by the recipients and the offspring first and then with some kind of link back to the donor. Sometimes it is actually driven the other way. It has been our experience that when those linkages one way or another have occurred, they have been fairly positive. The challenges have been in our own unit.

There has been a lot of intransigence at different levels and from different sides, because different members of different departments have different opinions. Although it is not our own personal experience, when we then go and look at, for example, Victoria, where there is an independent authority, that has taken some of those individual views out of it. I do not have any experience—I do not even have any statistics of how the Victorian Assisted Reproductive Treatment Authority is run. Perhaps you do, Liz. But stepping back and taking it out of that approach is why the argument for an independent authority is quite good.

**Ms HURRELL:** In respect of our experience with outreach to donors, I guess it is quite limited in a clinical context. There is not a huge number of people requesting this contact. The philosophy that the clinic I work in operates under is that outreach will occur if the donor has made some indication either in his original consent or by making subsequent contact that he would be willing to have contact with a donor-conceived

person. I guess that process of outreach is then about recontacting the donor and advising the donor there has been a letter or something left, and then it is a process of a slow exchange of information, and the counsellor's role in that process is mediation.

There are certainly examples elsewhere in Australia. A model I use is the Melbourne Royal Women's Hospital. It has a lot more experience in this, and the Victorian Assisted Reproductive Treatment Authority has used that model a lot in the way that they work in that they have a standard letter that they will send out to a past donor, inviting that person to make contact and that letter is sent by registered post. As I said, that is the beginning often of a slow process. Like any relationship, it involves laying a foundation for the terms that those people want to meet on. It involves ensuring that the expectations of both parties i.e. donor-conceived young person and the donor are similar, and then it is about exchanging information. It does have the potential to lead to families meeting or a donor-conceived adult meeting with their half genetic siblings. It has all sorts of potential, but it does not always realise that potential.

**CHAIR:** You mentioned earlier that donors do not really have a voice. In a previous inquiry and in this inquiry, we do not seem to have a lot of donors knocking on the door wanting to give us information. We are hearing a lot of information from one side, especially the donor-conceived individuals and representatives of that. Do you think that the Fertility Society of Australia would be able and prepared to facilitate contact with your members and with donors about trying to encourage them to help our inquiry?

Associate Professor BOWMAN: I guess the challenge is if they believe in their anonymity they are not going to present. That is the challenge.

**CHAIR:** They have an opportunity to come to an inquiry, a hearing like ours, where their information will not be public. It is a question for the Fertility Society of Australia. Is there an opportunity to facilitate that sort of contact? "No" is an answer.

**Ms HURRELL:** I am aware that the Victorian Assisted Reproductive Treatment Authority, at the request of the Victorian Government, had a campaign to invite donors to come forward and comment on the proposals that the Victorian Government is putting forward. Even a fairly well-funded media campaign and so on—it has brought a number of donors forward, but my understanding—and this is an understanding—is that it is about 20 or so donors. I may have to be corrected on that figure. It is not easy to get donors to come forward. May I say that even an inquiry like this, whilst it has had some profile, it has not had a huge media profile, and even the voluntary register in New South Wales has not had a huge media campaign. If donors were men who are now in their 50s or 60s who donated in their 20s or 30s, this may not be something that is high priority in their daily life. They also may not be aware of these things, given the profile of the campaigns that have been run in New South Wales.

**CHAIR:** To that point, the campaigns held in Victoria and New South Wales and the inquiries that have been had across a number of states are attracting those donors to come forth. That is why the question was if you could consist us to draw their version, because at the moment we are hearing from one side more than the other. We are here to make decisions for the future based on the information in front of us. It could be biased to one side, but that is because of the information provided, and we have tried. But you are right. That is why I am reaching out here and asking a more direct question.

**Ms HURRELL:** The Fertility Society of Australia is a group that represents the scientists, nurses, doctors and counsellors who work in the industry, and we do have a position for consumer representation. I guess we would need more information about how you wanted that to be promoted.

**CHAIR:** Perhaps if we write to you in the future and let you know exactly what we are thinking and you can respond to that.

Ms HURRELL: That sounds like a good suggestion.

**Mr NICK LALICH:** Following on from that, in your experience, has the number of donors dropped off since the new legislation? The information we are getting is that it has dropped.

**Ms HURRELL:** I think the answer is yes. The clinic settings that we work in only work with known donors. We only work with donors who are donors who come to the clinic with the recipient of their donation.

Associate Professor BOWMAN: Client-recruited donation, as opposed to clinic-recruited donation.

Ms HURRELL: What we are talking about in a lot of these cases is clinic-recruitment donation where the clinics themselves will recruit the donors.

**Mr NICK LALICH:** You mentioned the importance of the relevant agencies managing inquiries sensitively. What elements do you think are necessary in order to achieve this to keep it sensitive?

Ms HURRELL: One of the issues is the privacy of the issue. Sorry, that was outreach?

**Mr NICK LALICH:** I will read the question again. You mentioned the importance of the relevant agency managing inquiries sensitively. What elements do you think are necessary in order to achieve this?

Ms HURRELL: Inquiries to outreach the donors, is that the inquiries you are referring to?

Mr NICK LALICH: Managing inquiries from people outside. You said that privacy is one important thing.

#### Ms HURRELL: Privacy is utmost.

Associate Professor BOWMAN: We referred to this in the submission. The Health Department currently is performing a bureaucratic role of collecting a whole lot of names. From what I can see there is no resourcing within that instrument to handle anything like what Liz has been referring to in terms of the connections, the privacy, the counselling—all of those things—which takes a lot of resourcing, but ultimately, if you are going to do that properly you would argue that that is what the elements would be, so it is not just an Excel spreadsheet of names. We have listed some of the things in the submission of what that would require. Is that what you mean?

**CHAIR:** We have an agency like the Registry of Births, Deaths and Marriages that are great at collecting and maintaining data, but when it comes to counselling and counselling services, it is completely outside of their expertise and their ability.

# Associate Professor BOWMAN: Yes.

**Ms HURRELL:** In looking at the sensitivity of these situations, we are sometimes talking about young adults—if we are looking at working under the new Act and looking at the age of 18 as a cut-off—who are still achieving a sense of their personal identity, so there are issues about their identity that has to be handled sensitively. There are also members of families who may have siblings who do not want to be part of the process of donor linking, so the needs of the family also have to be acknowledged and managed sensitively. As I alluded to earlier, it is also about the fit between the donor's expectations and the expectations of the young person.

A young person who has grown up with a father in their life may have different expectations of meeting with a donor—it may be more about curiosity and wanting medical information—from those of a young person who has not grown up with a father in their life. They may be expecting more from the donor and some of those expectations might be quite unrealistic. They are all things that need to be handled very sensitively. In broader terms, when we are talking about linking half genetic siblings we must acknowledge that some young adults who are donor conceived may not have been informed. All those things must be handled with utmost privacy and concern for the individual's psychological needs.

**Mr GARRY EDWARDS:** You state that the Fertility Society supports the establishment of voluntary donor registers like those now operating in some assisted reproductive treatment clinics. How do they differ from the voluntary register run by NSW Health?

Associate Professor BOWMAN: Ultimately it is simply whether or not they are working. However it occurs—at a clinic or at the state or national level—it should be recognised that there are ways of communicating information, but they require resources.

Ms HURRELL: I understand that most of the voluntary registers established in clinics were established prior to the legislation. There was no legal requirement for their establishment, whereas the voluntary register established under the New South Wales assisted reproductive treatment legislation has that

legal umbrella. These registers were an attempt to provide the opportunity to link people when all parties consented. The reality of the voluntary register run by NSW Health is that it in turn refers back to the clinic of origin for counselling and linkage. In a sense, NSW Health refers back to the clinic for linking if there is a linkage on the New South Wales voluntary register. What happens in the clinics if they have a register is the same as is being implemented through the New South Wales assisted reproductive treatment legislation voluntary register. There is not a lot of difference in the way that they act or function. Again, I stand to be corrected because some clinics may be more aggressive in their outreach actions. We cannot speak for the way that every individual clinic functions.

**Mr GUY ZANGARI:** The Committee has received evidence about the many similarities between circumstances of adoptive persons and donor conceived persons. What is the main difference between the two and do you think that any elements of the model currently in place for managing adoption information could be used to manage donor conceived information?

Associate Professor BOWMAN: One of the main differences—and, of course, in the light of what has transpired this might not have been the case—is that in the adoptive process a child was born and an active decision was made whereas a donation involves a potential child and the decision is voluntary. That aside, there are other similarities. I am not an expert on the adoption legislation, but I understand both sides can impose vetoes.

**Ms HURRELL:** There are parallels, but there are also differences. The most significant is that with adoption a child was born as a result of an intimate act between two adults and at the beginning of that child's life both of the adults potentially had legal rights as the parent of that child. With donor conception there was a clinical treatment process and in effect the donor entered into a medical contract on the understanding that they were making an altruistic donation to help a couple or individual with fertility problems to achieve a pregnancy and would never have a legal right to that child or an expectation of contributing as a social parent to that child's existence. That is a very significant difference between the models.

**Mr GUY ZANGARI:** The second part of the question referred to the management of adoption information. Do you think the current adoption model could be used to manage donor conceived information? Do you think there are any elements that could be used for donor individuals?

# Associate Professor BOWMAN: I am not across adoption.

**Ms HURRELL:** The Fertility Society of Australia believes that a model linking donors and donor conceived persons should continue only if all parties consent. The adoption model does not acknowledge the need for the consent of all parties. I do not think there is a clear fit. The Post Adoption Centre is very impressive in the way that it negotiates and mediates the relationships between parents and their children who were adopted. However, it does not fit exactly; it is a different model.

**CHAIR:** Your submission states that the veto model is inadequate as part of the framework for managing donor conception information. Can you expand on the reasons for that?

Associate Professor BOWMAN: It is primarily because the information resides out of the unit where it might have been seen as well protected. It is now residing with an independent body, which may then be only one step away from another regulatory change and information could then be outed. That is the concern of many of the treating units.

**Ms HURRELL:** The veto model is inadequate in the sense that it does not provide suitable protection for donors. I am in no way suggesting that we are taking the side of donors against donor conceived young adults. The fact that that model does not provide protection for donors means that the donors' medical records would have to be held by a third party and there is therefore no way to guarantee the confidentiality of those records. As a society we are saying that there are different models that we should run with rather than the veto model. I also suggest that setting up situations where donors are being forced to have contact with donor conceived adults also may not be in the interests of all parties.

**Mr NICK LALICH:** Your submission highlights the importance of counselling as part of the process of managing information release. Do you think other types of services could be offered?

**Ms HURRELL:** There are other things that can be offered on a community level. I think there is a need for a lot of community education around donor conception. I think that in Victoria VARTA has been doing a lot of this sort of community education. I think there is still a lot of ignorance in the community which prevents donors from coming forth and putting their name on a register. I think there needs to be more awareness of what it means to come forward as a donor. There needs to be more information shared for families who are donor conceived about telling a child in a way that is going to work well for the family. This is not in place of counselling, this is another level of service that needs to be provided. I think VARTA has an excellent website and people who can advise and give information. It has a letterboxing service for donors and it provides support groups for young donor-conceived people. They are the other sort of services other than counselling that can be provided.

**Mr GARRY EDWARDS:** You note the benefits of VARTA and the Western Australian Reproductive Technology Council to both consumers and clinics. Do you think that either of those groups provides a good model for New South Wales? Which elements would you maintain or change?

**Ms HURRELL:** I think in our submission we have cited VARTA as the model that we would like to run with. That also means that resources have to be put into that model, and that is the hard thing economically I guess.

**CHAIR:** Last year the Committee visited Victoria and noted that its part of counselling is not resourced well and is almost like a rubber stamp counselling process that allows information to be provided at a later stage. You say VARTA is the model—

Ms HURRELL: VARTA has registered counsellors with skills in donor-linking.

**CHAIR:** Yes, but because of the Privacy Act those counsellors go to a meeting with, say, a donorconceived individual who is seeking information from Deaths, Births and Marriages technically blind without any information prior to that meeting. They are limited in the type of questions they can ask, and what they are trying to work out. By the end of the process it is a tick that the donor-conceived individual has done counselling, off they go and get information from Deaths, Births and Marriages. To me the counselling seemed like a rubber stamp process rather than genuine counselling in preparing an individual for the information they are about to receive.

**Ms HURRELL:** My perception is not exactly the same as yours. My awareness of some of the counsellors at VARTA—certainly a particular counsellor who is the president of ANZICA—is that they work very much in the donor-linking model of ANZICA. Yes, I understand there is sometimes difficulty in getting information about the donor so the young person might come along, but that does not mean that the counsellor has a whole lot of identifying information about the donor. Is that what you are referring to?

**CHAIR:** That the is correct.

**Ms HURRELL:** No, they do not because that information is not really available, just as in New South Wales when a donor-conceived person comes to me, I do not have any information about the donor. But it is the beginning of a process and that counselling is about exploring the needs of that donor-conceived young person, about exploring their expectations, about exploring their fit within their family situation and then it is about helping that young person with the process of linking with the donor. It might now be about helping that young person put their name on the voluntary register but it is also about seeking out the limited information you can access about the donor, and then building on that. No, it is not an ideal model in the sense that the counsellor has got all this information about the donor and they can talk to the young person about it, that is not how it works because that information currently is not available in Victoria.

**Mr GUY ZANGARI:** You state that if an independent body were established a donor register it may possibly retain a clinic's records if the clinic were to close. Does that mean that you believe it should not already hold that information? What information do you envisage such a body as holding?

Associate Professor BOWMAN: In a majority circumstances, either because if you are dealing in a hospital-based system, a system kind of exists. In a private setting a private clinic might buy another private clinic and therefore acquire records and it has to take on those responsibilities. That is the usual model that is rolling but we recognised that in a small number of circumstances—and there are examples of that here in Sydney—when a private individual's practice has closed what becomes of those records? It was not that we

thought that was the primary aim to take everybody's records, it was more that if there were no other repository of records that that is where that would exist, notwithstanding that you would need some regulatory safeguards around that.

**Ms HURRELL:** In Health we cannot just handover records. There is privacy legislation which protects those records. Yes, it is not perceived as necessarily the repository of all of those records.

**Mr NICK LALICH:** Are you aware that post adoption counselling has recently made freely available by the Federal Government? Do you see any parallels between that and donor conception counselling?

**Ms HURRELL:** There are some parallels but I think we have covered them. The experience of a child who was adopted basically involved a very traumatic experience at birth for both the mother and the child and that child was then placed with another family. In a sense, donor conception does not have that level of trauma of separation of mother and child. In the donor conception model there are still issues of genetic curiosity.

**Mr GARRY EDWARDS:** You state in your submission that it is not appropriate for clinics to fund the donor register. Without suggesting this to be the case, what would be your response to the suggestion that they make a contribution?

Ms HURRELL: I work in a public hospital clinic, do I have to answer that question?

## Mr GARRY EDWARDS: No.

**Ms HURRELL:** There are also private clinics but, yes, how can I put it? You could put that suggestion to clinics but they are private organisations, private businesses, some are private corporations. Some may come to the party, some may not be able to come to the party. I really could not comment on that.

Associate Professor BOWMAN: It is likely in a private setting that those costs would then be passed on to the consumer.

**Ms HURRELL:** There is something in that proposal that suggests that there is a sense that clinics should do this in order to kind of make-up for past practices. I do not think that kind of concept can apply.

Associate Professor BOWMAN: Particularly if you look—in at least two private setting insemination clinics from whom the offspring who are now the subject of these sorts of discussions, do not exist anymore, and they have not been taken over by anybody else.

CHAIR: Is there anything else you would like to add?

Associate Professor BOWMAN: Just reiterating that those of us who have been around for a while have seen the three or four evolutions of this as good practice emerges and it is always the story that in the 1970s what was seen as good practice is quite different to the twenty-first century. It is us trying to sort of manage that evolutionary process as best as possible, which is trying to separate that out from a concept that it wasn't that something was done incorrectly or badly it was just in the light of a completely different paradigm then.

My experience of being party to, for example, the Federal Senate inquiry into donor-conceived individuals was that somehow there was this terrible wrong done and yet this is all about things that were done in good faith both from the donor's perspective and from the treating people's perspective, and quite frankly from the parents of the donor-conceived individual's perspective. Everybody was doing what they thought was the right thing and to undo some things that were done in good faith then is the challenge we have. We also want to state that we are not washing our hands of the problem; we are very keen to manage this in the hindsight of that evolutionary experience that we have and to assist the Government with that.

Ms HURRELL: This is a complex situation and there isn't a simple one-stop answer; it needs to be on many dimensions.

**CHAIR:** The Committee members quickly understand that. I thank you both for your time today. The Committee secretariat will send you a couple of questions on notice.

Ms HURRELL: That will be fine.

CHAIR: Your replies will form part of your evidence today. I hope you are happy with that.

Associate Professor BOWMAN: That is fine.

(The witnesses withdrew)

(The Committee adjourned at 4.23 p.m.)